Hospital User Manual

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Version 9

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1 Document Overview

This user manual is designed as a guide for hospital staff required to access and enter data into the Australian Stroke Clinical Registry (AuSCR), an online web-based tool (referred to as **AuSCR Database** throughout this document). Users are assumed to have a basic level of computer skills and be familiar with browsing the internet. After logging into the secure AuSCR Database, there are several steps to enter data, first each patient must be created (New Patient), then each episode must be recorded (Episode Details). This manual will guide staff through each of these steps, and also explain other user options, such as printing reports and importing and exporting your hospital's data in and out of the AuSCR Database.

2 Contact Details

Further information can be found on the AuSCR website http://www.auscr.com.au or by contacting the AuSCR central data management office, located at The George Institute for International Health in Sydney.

Assistance from the AuSCR office is available from the helpdesk Monday to Friday between 9am and 5pm.

Contact can be made via:

- Email: admin@auscr.com.au
- Telephone: (02) 9993 4592

3 Background Information

A PowerPoint presentation can be accessed electronically by contacting the AuSCR office or accessing the online version from the website www.auscr.com.au. The presentation provides an overview of the AuSCR project and includes information on the purpose, governance, data collected and benefits of participating in AuSCR. First-time users are encouraged to view the presentation prior to accessing the AuSCR Database.

4 The Opt Out Consent Model

For AuSCR to ensure quality data, meticulous attention must be given to ensuring that complete data are collected on all patients, and that all eligible patients with stroke are included in the AuSCR Database. If AuSCR collects an incomplete set of patients from a hospital, strong biases may occur and the usefulness of the data for the monitoring and planning of health care delivery is limited.

To achieve this, and to include as complete set of patients as possible, AuSCR uses an opt out consent model. This means that all patients admitted with a stroke or TIA at your hospital should be entered in the AuSCR Database unless they, their parent/guardian or next-of-kin formally request not to be included.

To ensure informed consent, and in line with the ethics approval at many sites, an information poster and brochures describing the purposes of AuSCR are available

on the stroke and general medical wards at each participating hospital. The brochures outline the purposes of the registry and describe how patients may opt out of being included.

It is the responsibility of the treating hospital to provide the Information Sheet to all patients. This information sheet clearly explains the AuSCR project and how patients may *opt* to have some or all of their data removed from the AuSCR Database. The process for providing this information to patients within your hospital should be:

- All patients or their relatives are provided with a copy of the AuSCR information sheet (the version must be the version approved at your hospital (See Attachment 1)). This may be provided in your ward's admission pack;
- If a patient requires an interpreter to understand medical information, AuSCR recommends that an interpreter be used to explain the information, in line with your usual hospital practices;
- For those patients aged under 18 years, the information sheet should be given to the parent/guardian;
- Where a patient lacks competence to consent, the information sheet should be given to their next-of-kin;
- It is important to clarify that patient/guardian or next of kin may request to remove, or opt out, any information at anytime, and that this right does not end on discharge from hospital (section 16);
- If a patient, their parent/guardian or next-of-kin asks to opt out of the Registry they can do so by contacting the AuSCR office by telephone or email (as described in the information sheet). They may also sign the opt out form (See Attachment 2);
- It is important to clarify with all patients/guardians/next of kin which variables they would like removed; it is possible to keep only details about their stroke in the database while removing all personal and identifiable information about the patient;
- The signing of the opt out form (see Attachment 2) ensures that a record of the patient's request to be removed from the AuSCR Database remains on their medical file for all future admissions. Thus, the AuSCR office will request that a form is completed for each opt out received. The original, signed copy of the opt out form should be kept in the medical record and a copy faxed to the AuSCR office **secure fax number on (02) 8507 2531**.

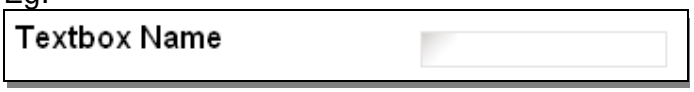
5 General Information about the AuSCR Database

The following information should be understood by all AuSCR Database users:

- The term **click** is used throughout this manual to refer to a **left mouse click.**
- Mandatory fields are denoted by a **red asterix** (*). If you fail to enter data for a mandatory field, an error message will flash onto the screen when you try and save data on that particular page of the AuSCR Database.
- Blue labeled buttons are used throughout the AuSCR Database and require a left mouse click to activate.

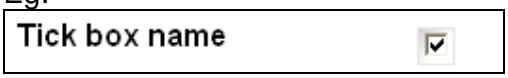
Data are entered into the AuSCR Database using:

1) **Text boxes** – a blank white box which you type data in.
   - Before typing data you must ensure the cursor (indicated by a flashing black bar) is in the correct field text box.
   - To move the cursor to a text box click in it.
   - The **Tab** button on your keyboard can be used to move to the next field text box.
   - Eg:



2) **Drop down lists** – a list of options which you select from
   - These are white boxes which contain either a default option or the words **Please Select** and a small blue box with a down arrow.
   - To select an option, click the down arrow and then **click the option required**.
   - For large option lists, you can either scroll down the list using the blue scroll bar to the right of the list (click and hold the left mouse button down while moving the scroll bar down the page until the option required appears) or type in the first letter of the option you require.
   - Eg:

3) **Tick boxes** – a small white box which you click in to mark with a tick.
   - To remove the tick click in the box a second time.
   - In some instances, where it is not applicable, the tick box may be inactivated.
   - Eg:



4) **Radio buttons** – a small white circle which you click in to mark with a dot.
   - If there is more than one radio button for a field, only one button can be marked.
   - Clicking an alternative radio button for a field will unmark all other radio buttons for that field.
   - Eg:

5) **Calendar** – Dates can be entered by either typing them in the text box or by using an embedded calendar to select the date. **The use of the calendar is the preferred option to reduce errors.**

- To use the calendar, click the calendar icon to the right of the text box and click the date required.
- Click the **Today** button at the bottom of the calendar to enter today's date.
- Click the arrows at the top of the calendar to navigate as follows:

  << to move back by one year

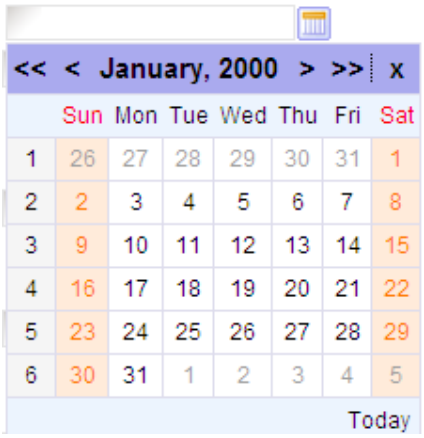
  < to move back by one month

  > to move forward by one month

  >> to move forward by one year

  x to close the calendar

- Eg:



6) **Episode –** An 'Episode' provides the details of care provided in hospital to a patient. Patients' can have multiple episodes e.g. if they are readmitted to hospital for a recurrent stroke. This is where patient clinical data are recorded.

   It is preferable that episodes are recorded in chronological order; however, if the episode IDs are not sequential, it is not a problem.

7) **Saving Data– Pressing Enter** at any time during the data entry assumes that all variables have been completed and the "save" function is actioned.

8) **Variable Definition –** All variables collected are defined in the AuSCR Data Dictionary (Attachment 4). Variable definitions and formats, where possible, are consistent with the electronic National Health Data Dictionary (METeOR) (http://meteor.aihw.gov.au/content/index.phtml/itemId/181162)

   Where a (METeOR) definition does not exist we have used the definition from the National Stroke Foundation Audit.

6 How to Obtain a Password

Each hospital will have a Hospital Administrator created by the AuSCR office. The Hospital Administrator will then be able to create all Hospital users.

To request a user name and password to access the AuSCR Database the Hospital Administrator must:

1. Complete a **User Request form** and email or fax it to the AuSCR office. Contact the AuSCR Office to have a form sent either by email or fax.
2. Once created a "Registration Alert" email will be generated with your username and password in an email back to you.
3. You must change the generic password given to you when you first log in to the AuSCR Database.

The AuSCR office contact:

Email: AuSCR Project Coordinator (admin@auscr.com.au)

Fax: (02) 9993 4592

To become a Hospital User:

1. Complete a **User Request form** (Attachment 5) and email or fax to the AuSCR Hospital Administrator for your hospital.
2. Once created a "Registration Alert" email will be generated with your username and password in an email back to you.
3. You must change the generic password given to you after you log into the AuSCR Database for the first time.

How to create a Hospital User if you are a Hospital Administrator

1. Click the **Administration** button on the navigation menu
2. Click the **Users** button on the navigation menu
3. Scroll down to **New User** button at bottom of the **User List**
4. Click on **New User** button (Figure 6.1)
5. Complete new user details on **User** page (Figure 6.2)
6. Create a **generic password**. The password must be longer than 4 and shorter than 9 characters and contain both letters & numbers!
7. Click the *Receive Email* tick box
8. Select Hospital User in *Role* text box
9. Select your *Hospital* from the drop down list
10. Click the **Save** button
11. An email will be automatically generated and sent to the email address you have entered (Figure 6.3)

Figure 6.1 Creating New User Page

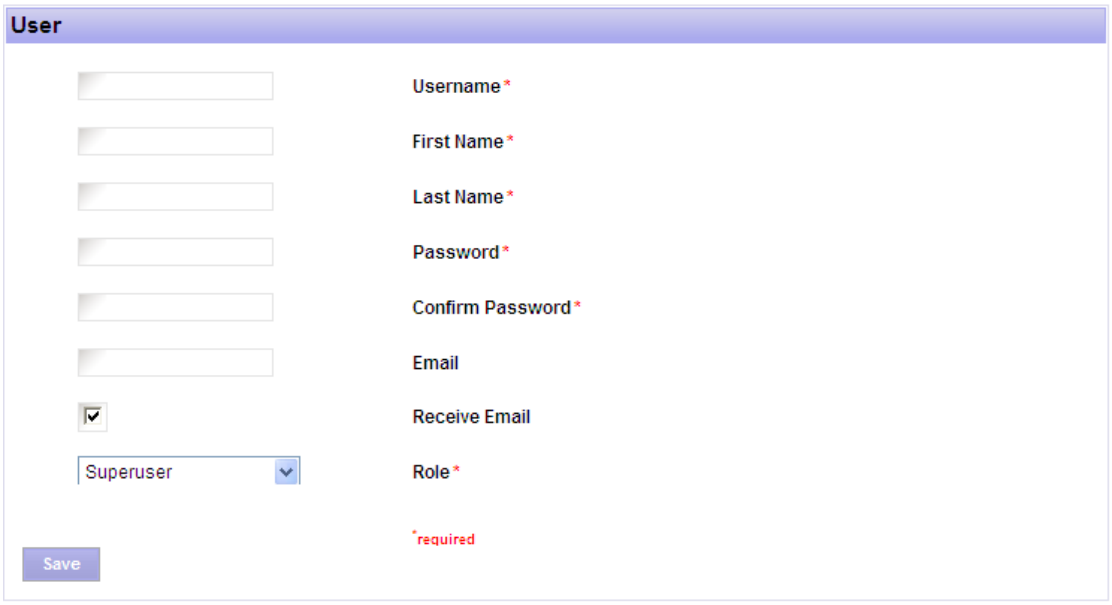


Figure 6.2 User Details Page (example)

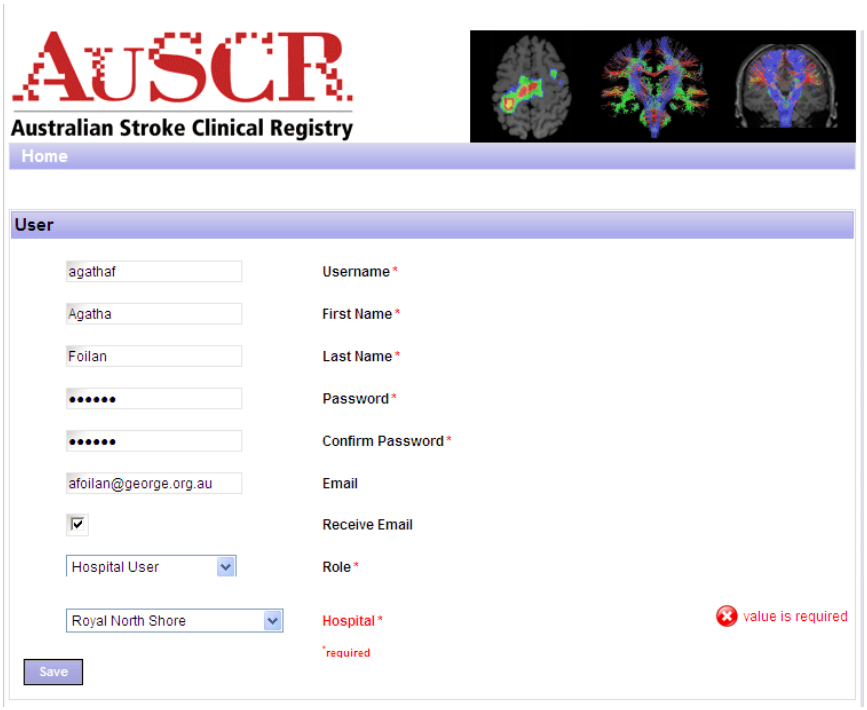
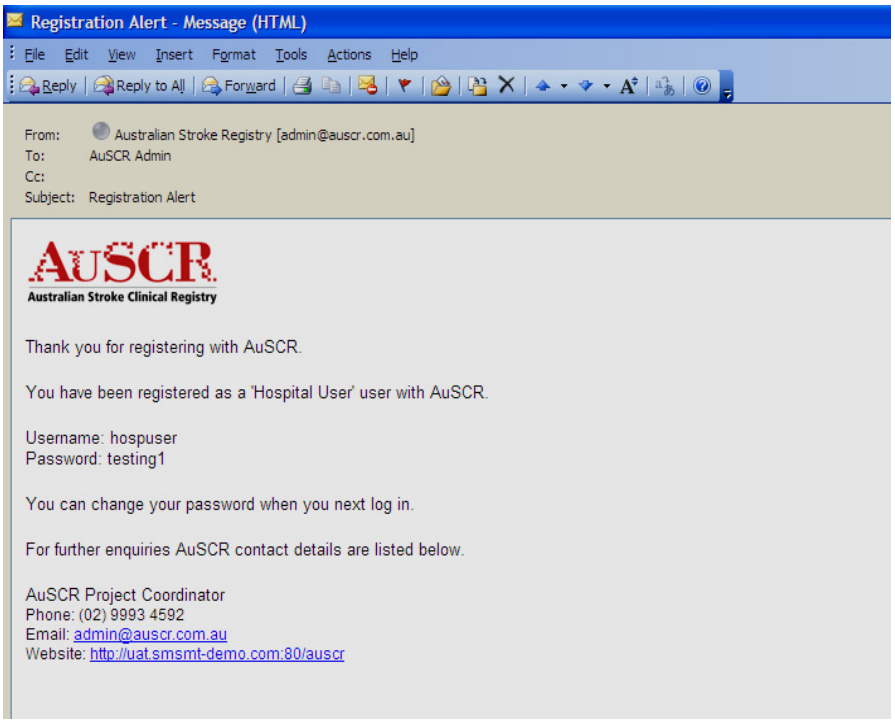


Figure 6.3 Registration Alert Email


Registration Alert - Message (HTML)
File Edit View Insert Format Tools Actions Help
Reply Reply to All Forward
From: Australian Stroke Registry [admin@auscr.com.au]
To: AuSCR Admin
Cc:
Subject: Registration Alert
AUSCR
Australian Stroke Clinical Registry
Thank you for registering with AuSCR.
You have been registered as a 'Hospital User' user with AuSCR.
Username: hospuser
Password: testing1
You can change your password when you next log in.
For further enquiries AuSCR contact details are listed below.
AuSCR Project Coordinator
Phone: (02) 9993 4592
Email: admin@auscr.com.au
Website: http://uat.smsmt-demo.com:80/auscr

7 How to Change your Password

To change your password:

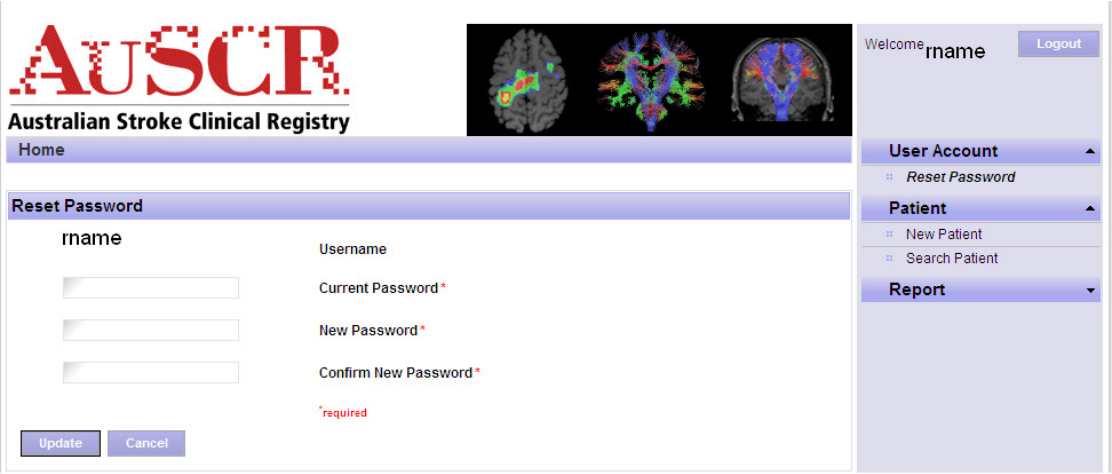
1. Click the **User Account** button on the navigation menu.
2. Click the **Reset Password** button on the navigation menu and the **Reset Password** page will be displayed (Figure 7.1).
3. Type your current password in the *Current Password* text box.
4. Type your new password in the *New Password* text box.
5. Re-type your new password in the *Confirm New Password* text box.
6. Click the **Update** button to save your new password (or click the **Cancel** button if you do not want to change your password).

Important Note: If you forget your password, email the AuSCR office admin@auscr.com.au stating that you have forgotten your password and include:

- First name
- Last name
- Role in AuSCR (e.g. Hospital User)
- Hospital name.

A new password will be emailed to you.

Figure 7.1 Reset Password Page



8 Logging In

Once you have obtained your username and password via an email you will be able to log into the AuSCR Database.

You must only ever access the AuSCR Database using your own username and password.

To login to the AuSCR Database:

1. Open a web browser and navigate to: http://www.auscr.com.au. The AuSCR **Home** page will be displayed (Figure 8.1).
2. Click **Registry Login** towards the bottom of the right hand side of the page and the **Login** page will be displayed (Figure 8.2).
3. Type your username in the *Username* text box.
4. Type your password in the *Password* text box.
5. Click the *Remember me* tick box if you want the computer to automatically show your username the next time you login to the AuSCR Database.

   Important Note: you will still need to enter your password each time you login. Only use **"Remember me"** function if you are the only person who will be entering data on the computer you are using.
6. Click the **Login** button.

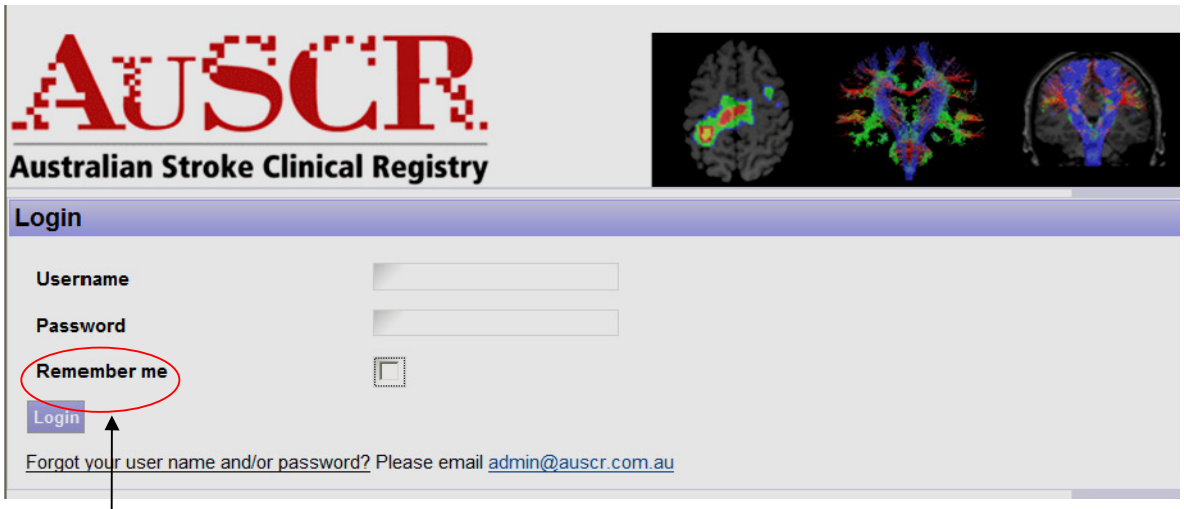
Important Note: The system will timeout after 15 minutes of inactivity and you will be required to login again.

Figure 8.1 AuSCR Home Page

AuSCR
Australian Stroke Clinical Registry
Home
Patients and Family Members
Health Professionals
Research
AuSCR
Contact
Search
PATIENTS & FAMILY MEMBERS
Learn about how you can support the Australian Stroke Clinical Registry and how we protect your personal information. (read more)
HEALTH PROFESSIONALS
Find information on the benefits of AuSCR to health professionals. Learn how your hospital can participate in AuSCR. (read more)
RESEARCH
Learn about the many benefits of AuSCR for researchers. You will also find links to Research Publications and Proposal submission guidelines. (read more)
AUSCR
Find out about AuSCR , our governance structure and sponsors. Read through our FAQ section and browse our Policy Documents and Reports. (read more)
Latest News
November 3rd, 2010
Latest News Title
AuSCR Newsletter - November 2010 issue 9 is now available
Download Media Release
November Newsletter
Latest annual report
Free Call: 1800 673 053
Web: www.auscr.com.au
Home
The Australian Stroke Clinical Registry (AuSCR) is a collaborative national effort to monitor, promote and improve the quality of acute stroke care. We believe that by working together, patients, families, clinicians and researchers can make a difference in the lives of people affected by stroke.
The data collected will guide quality improvement interventions in hospitals, reduce variations in care delivery and, ultimately, provide evidence of reduced deaths, disability, and recurrent stroke. The Australian Stroke Clinical Registry will ensure best practice stroke care in Australia.
The Australian Stroke Clinical Registry collects data from participating hospitals across Australia using an online web tool. Hospitals can use the online tool to:
store their own patients' data
provide clinicians with downloadable reports summarising their patients' data
allow hospitals to export their data for local analyses; and
provide annual performance reviews, newsletters, and publications.
To access the Australian Stroke Clinical Registry, you need to be a registered participating hospital with approved log-in access. Please contact admin@auscr.com.au to enquire about participating.
If you are a registered participating hospital, please use the REGISTRY LOGIN button to access the online web tool and database.
The Australian Stroke Clinical Registry office staff are available on (02) 9993 4592 during AEST business hours.
Download Brochure
Registry Login
CLICK HERE
Consortium Partner
Home | Patients & Family Members | Health Professionals | Research | AuSCR | Site Map | Contact Us
website: iecom Group
Australian Stroke Clinical Registry (AuSCR) Copyright 2009 - All right reserved

Click here

Figure 8.2 Login Page



See Note under point 5

9 Navigation Menu

Once you have logged in, the AuSCR Database **Home** page will appear with the navigation menu displayed on the right hand side (Figure 9.1). The navigation menu then appears on each page while you are logged in. Table 9.1 briefly describes the features of the navigation menu.

The word **Home** also appears in a blue bar at the top of each page (under the AuSCR logo). Clicking the word **Home** will take you back to the **Home** page.

Figure 9.1 Navigation Menu

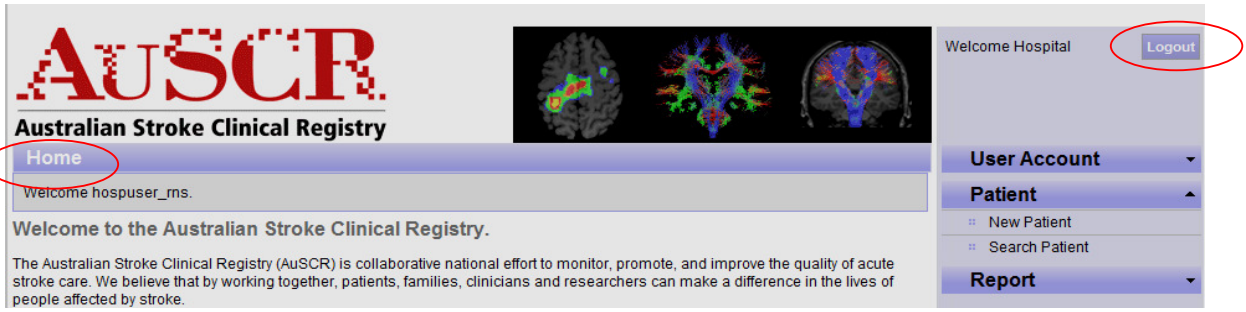

AuSCR
Australian Stroke Clinical Registry
Welcome Hospital
Logout
Home
User Account
Patient
Welcome hospuser_rns.
New Patient
Search Patient
Welcome to the Australian Stroke Clinical Registry.
Report
The Australian Stroke Clinical Registry (AuSCR) is collaborative national effort to monitor, promote, and improve the quality of acute stroke care. We believe that by working together, patients, families, clinicians and researchers can make a difference in the lives of people affected by stroke.

Table 9.1 Features of the Navigation Menu

Navigation Menu		Features Provided	Access
Logout		This button allows you to securely log out of the AuSCR Database	Hospital User
User Account	Reset Password	Enables you to change your password	Hospital User
Patient	New Patient	Allows you to add a new patient including personal information, addresses, contacts and episode data	Hospital User
	Search Patient	Allows you to search for an existing patient by first name, last name or medical record number	Hospital User
Report	Reports	Allows you to download pre-specified hospital reports. Please note that the data in these reports have not been verified by the AuSCR office and are for internal purposes only.	Hospital User
Data	Import Excel	Allows for XML import from hospital database to AuSCR	Hospital Administrator
	Export Excel	Allows for export from excel spreadsheet of “raw” data from your hospital input for manipulation.	Hospital Administrator

10 Adding a New Patient

To add a new patient:

1. Click the **New Patient** button on the navigation menu and the **New Patient** page will be displayed (Figure 10.1).
2. Type the patient's *First Name, Last Name* and *Date of Birth* into the appropriate text boxes.

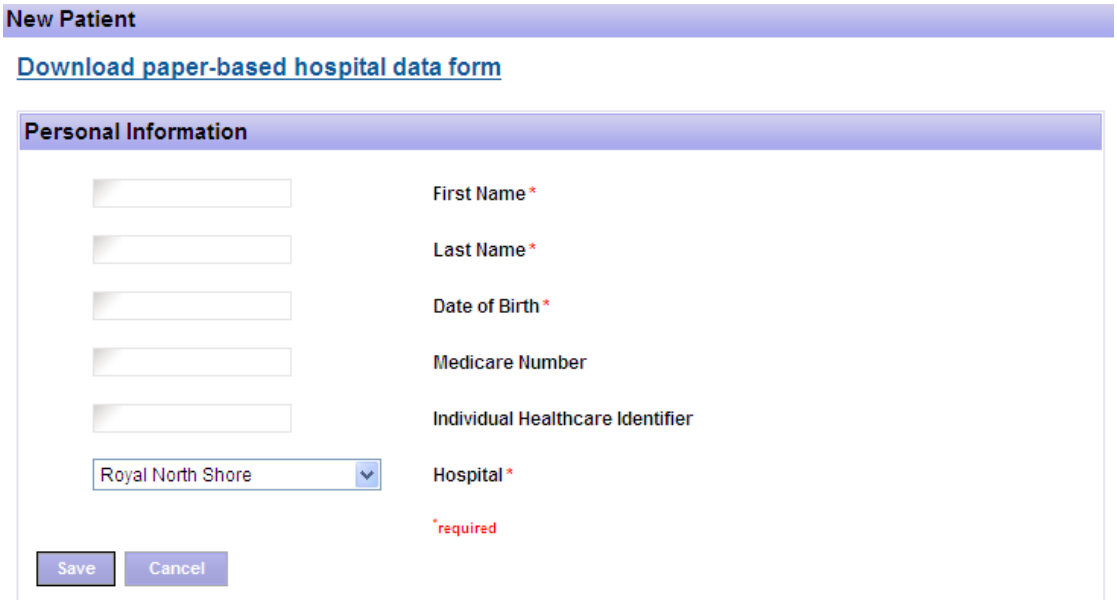
Important Note: These fields are mandatory, as indicated by the * next to them.

3. Type in the patient's *Medicare Number* (if known).
4. **Do not complete the Individual Healthcare Identifier. Please leave blank.**
5. **Stop and check all details against the medical record before saving.** Once saved a Patient ID link within the database will be created and cannot be changed.
6. Once the details have been checked, click the **Save** button to save the new patient's personal information (or click the **Cancel** button if you do not want to add a new patient).
7. Once the new patient has been saved, a **Patient Record** page will be displayed (Figure 10.2).

Important Note:

- The patient's name, date of birth and Medicare number **cannot be edited once saved.** If an error is made in these fields, the incorrect 'New Patient' must be deleted and a 'New Patient' must be created with the correct details entered.
- If you have noted a minor correction, such as a change of case to a correctly spelt name, you may request that AuSCR office fix these minor corrections. Please prepare a list of all the changes and email them to the Project Coordinator for attention to admin@auscr.com.au
- If you enter a new patient with the same *First Name, Last Name, Date of Birth* and *Medicare Number* as an existing patient, the system will automatically find the existing patient record and display their details for editing. To create a new episode of care for an existing patient, refer to **section 11 - Adding a New Episode.**

Figure 10.1 New Patient Page



The **Patient Record** page is used to add further patient information under the headings; **Personal Information**, **Address** and **Contacts** (Figure 10.2).

To add personal information:

1. Select the patient's *Title* from the drop down list.

   Important Note: Once title is selected, the gender will appear automatically.

2. Type in the *Hospital Medical Record Number.*

   Important Note: This is a mandatory field.

3. Select the *Gender* if the title selected is *Dr* or if the title is unknown.

   Important Note: For all other titles the gender cannot be altered.

4. Type in the *Phone Number* (including area code) and *Mobile Number*.

   Important Note: In the case of international landline phone numbers there is only space for 10 numbers, therefore only the phone number can be entered; exclude the international and the area codes.

5. Select the *Aboriginal/Torres Strait Islander origin* from the drop down list.

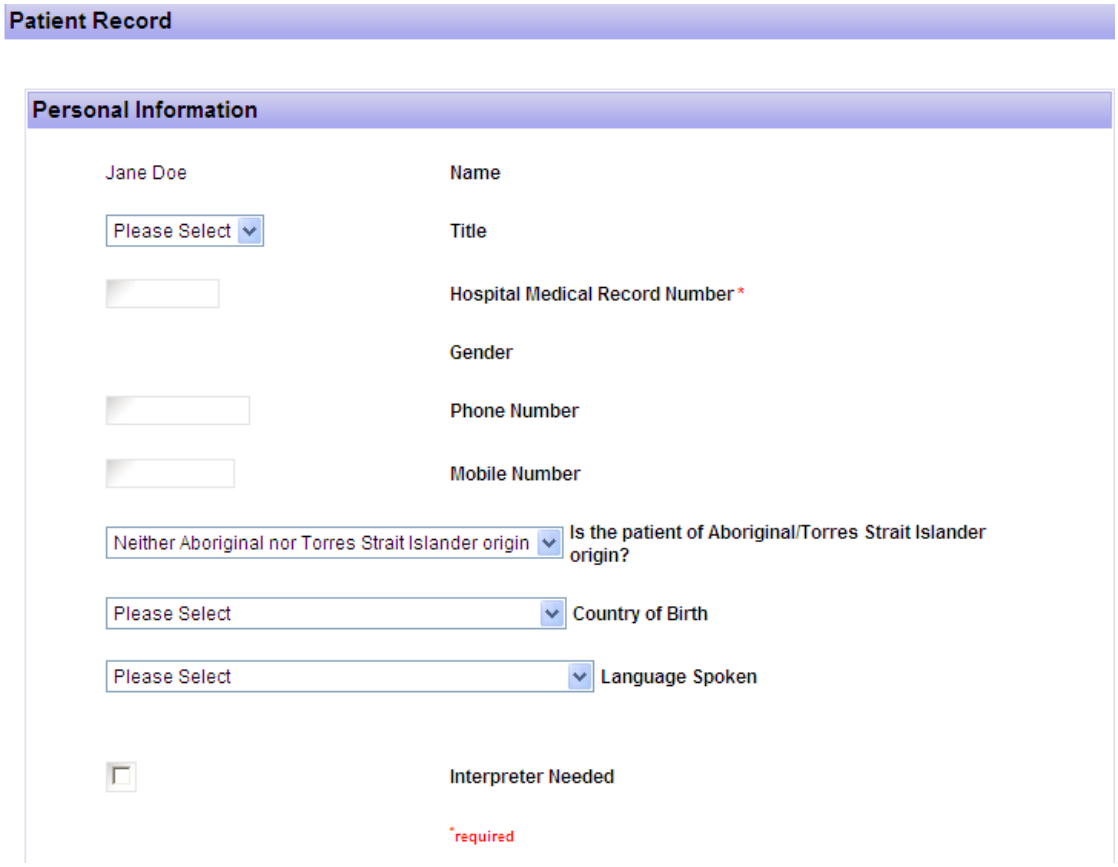
6. Select the *Country of Birth* and *Language Spoken* from the drop down lists.

   Important Note: The 10 most common countries/languages appear at the top of the lists with all others listed below in alphabetical order. Typing in the first letter will move you to the next country/language in the list starting with that letter. Each time a new letter is typed you will be moved to the next country/language starting with that letter.

7. If required, click the *Interpreter Needed* box to mark it with a tick.

Important Note: This box cannot be marked if *English* is selected as the *Language Spoken*.

Figure 10.2 Patient Record Page, Personal Information



To add addresses:

1. Click the *Mailing Address* tick box if the address being entered is to be used as the mailing address. At least one address has to be ticked as a mailing address.
2. Select the *Address Type* from the drop down list.

Important Note: The default option is *Home*.

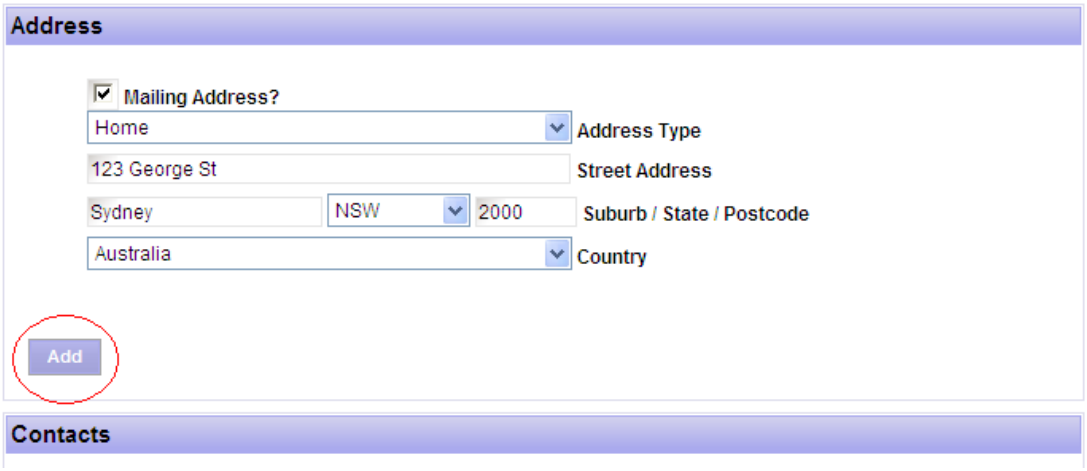
3. Type in the *Street Address* in the Street Address text box
4. Type *Suburb* into the Suburb text box.
5. Select the *State* from the drop down list (or Overseas if applicable).
6. Type the *Postcode* into the Postcode text box.

Important Note: Once the State has been selected only postcodes eligible for that State can be entered.

7. If it is an overseas address, select “Overseas” for the *State* and this will allow free text in the *Postcode* box to enter an overseas postcode.
8. Select the *Country* from the drop down list.

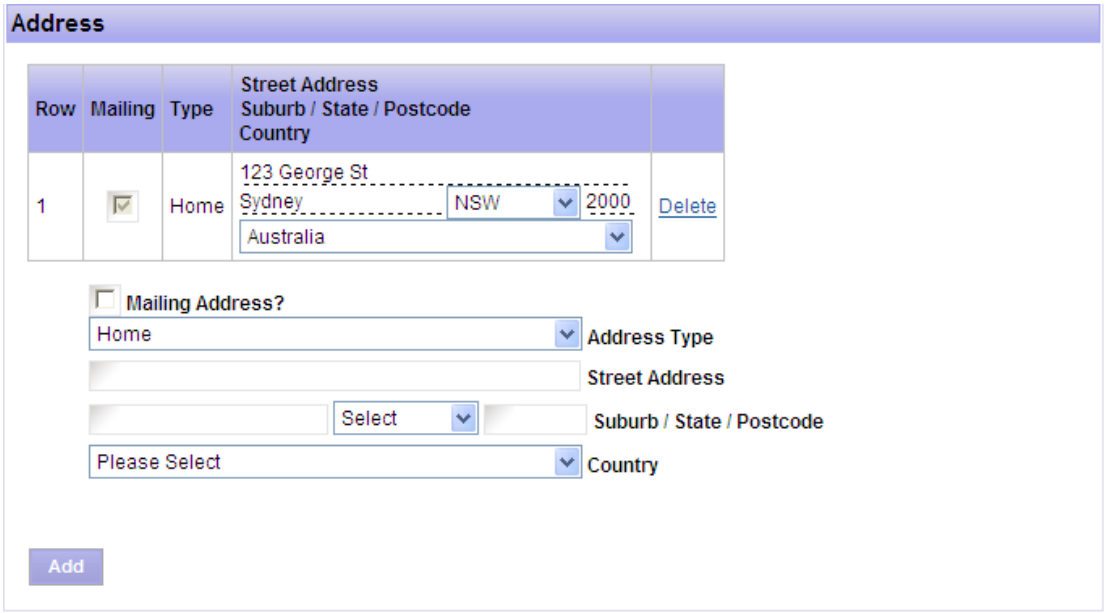
9. Additional addresses can be added by following steps 1-8 above for each address to be added after clicking the **Add** button at the bottom of the Address section (Figure 10.3).

Figure 10.3 Patient Address Section



Important Note: Any existing addresses can be edited in the table by clicking directly on the data to be changed and altering it as necessary. Addresses can also be deleted by clicking the *Delete* link to the right of the corresponding address. A Warning message will display once the *Delete* link is clicked, asking you to confirm that you want to delete the address. Click the **Yes** or **No** button to confirm or cancel the deletion.

Figure 10.4 Patient Address Table



Outcome determination is the most fundamental requirement of any clinical registry, including AuSCR.

In AuSCR, out of hospital outcomes are determined by contacting patients three months after discharge and asking a small number of key questions. It is very important that we are able to contact patients after they leave hospital. Therefore, at least **two contacts must be recorded in addition to the patient's own address** to avoid loss to follow up.

To add contacts:

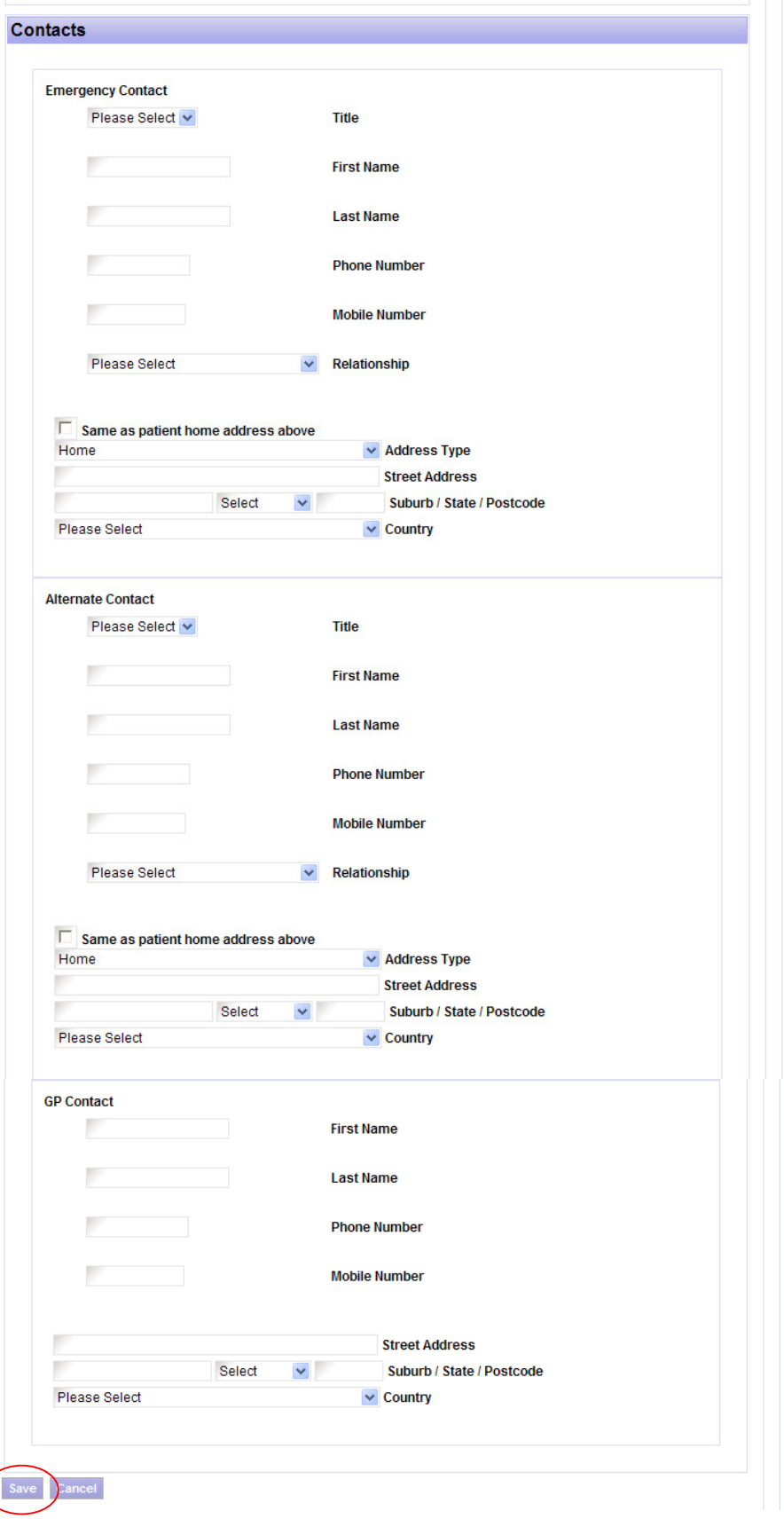
1. Select the contact's *Title* from the drop down list and type in their *First Name, Last Name, Phone Number* and *Mobile Number***.**
2. Indicate the *Relationship* to the patient (for Emergency and Alternate Contacts) by selecting one of the options in the drop down list.

Important Note: If *Other Relative* is selected, an *Other Relative* text box will appear which should be typed in to specify the relationship to the patient.

3. If the Contact's address is the same as the patient address click in the **Same as patient home address above** tick box.
4. Complete address detail entry (refer to: **To add addresses** section above).

Important Note: Once all of the data has been entered, click the **Save** button at the bottom of the page to save the information on the **Patient Record** screen. An **Information** page will be displayed showing all information entered for the patient. (Figure 10.5)

Figure 10.5 Patient Contacts Section



11 Adding a New Episode

The AuSCR Database requires that clinical information data is recorded as a separate episode of care.

Patients may have multiple admissions for stroke or have a stroke while in hospital for another condition. A new episode should be recorded for every new stroke event experienced by an individual patient.

If a patient has already been recorded in the AuSCR Database at your hospital you will be made aware of this once you have entered their details (refer to section 10 – Adding a New Patient). Refer to the AuSCR data dictionary for definitions, explanation and help notes on all the variables in the database.

To add a new episode:

1. Click the **New Episode** button at the bottom of the patient **Information** page and the **Episode** page will be displayed allowing for the entry of **Admission**, **Clinical, Discharge** and **Death Information**.

Admission Information (Figure 11.1)

If the patient was transferred from another hospital, or has a stroke while in hospital, refer to the data dictionary for correct data and time entries on the different scenarios of admission information, to ensure consistency.

1. Type (or use the calendar) for the following **Admission Information** and indicate whether each date or time is *Accurate* or an *Estimate* by clicking one of the corresponding radio buttons:
   - *Date of arrival to Emergency Department*
   - *Time of arrival to Emergency Department (ED):* enter the time the patient arrived in the ED of the Hospital, which has been electronically generated, on the emergency face sheet. If this time is not available use written documentation by nursing or ambulance staff. If there is conflicting data, use the earliest time recorded.
   - *Onset of stroke date*
   - *Onset of stroke time*
   - *Date of admission to hospital:* Enter the date the patient arrived in the ED of the *First* hospital. In some cases, (i.e. those patients who are observed in Emergency before the decision to admit is made) the date will not correspond with the date of admission to hospital. Take care to record the date of arrival in the ED, not the date of admission to the hospital – the two may differ if the patient arrives close to midnight and is actually admitted the following day.
2. Select the appropriate response from the drop down lists for each of the following questions:
   - *Was the patient transferred from another hospital?*
   - *Did this stroke occur while the patient was in hospital?*

- *Was the patient able to walk independently on admission?*
- *Is there documented evidence of a previous stroke (focal neurological signs persisting for more than 24 hours)?*

Notes for recording dates

- The format used for date is always DD/MM/YYYY
- Each date must be marked as *Accurate* or *Estimate* by clicking the corresponding radio button
- If the *Accurate* (exact) date is unknown and not obtainable, the *Estimate* radio button below the entered date should be clicked.
- When **the day is unknown** but the month and year are known, the date should be recorded as **01/MM/YYYY** and the *Estimate* radio button below the entered date should be clicked.
- When **only the year is known,** the date should be recorded as **01/01/YYYY** and the *Estimate* radio button below the entered date should be clicked.

Notes for recording times

- The format used for time is always the 24 hour clock with a colon automatically inserted to separate hours and minutes (hh:mm).
- Table 11.1 provides hints for recording time.
- If an exact time cannot be recorded (i.e. not in the chart or proxy/ family does not know), the best estimate should be given. Descriptions of time such as "two hours prior to arrival", "about 1 hour ago" or "approximately 2 and half hours ago" are specific enough to perform a calculation or express a time as *Exact*.

  If a time cannot be clearly determined, use the following guidelines (Table 11.2) for estimating times in conjunction with the time the note was recorded (or the time of arrival if not noted).
- As the last resort, **if a time is unknown, enter '99:99'.**

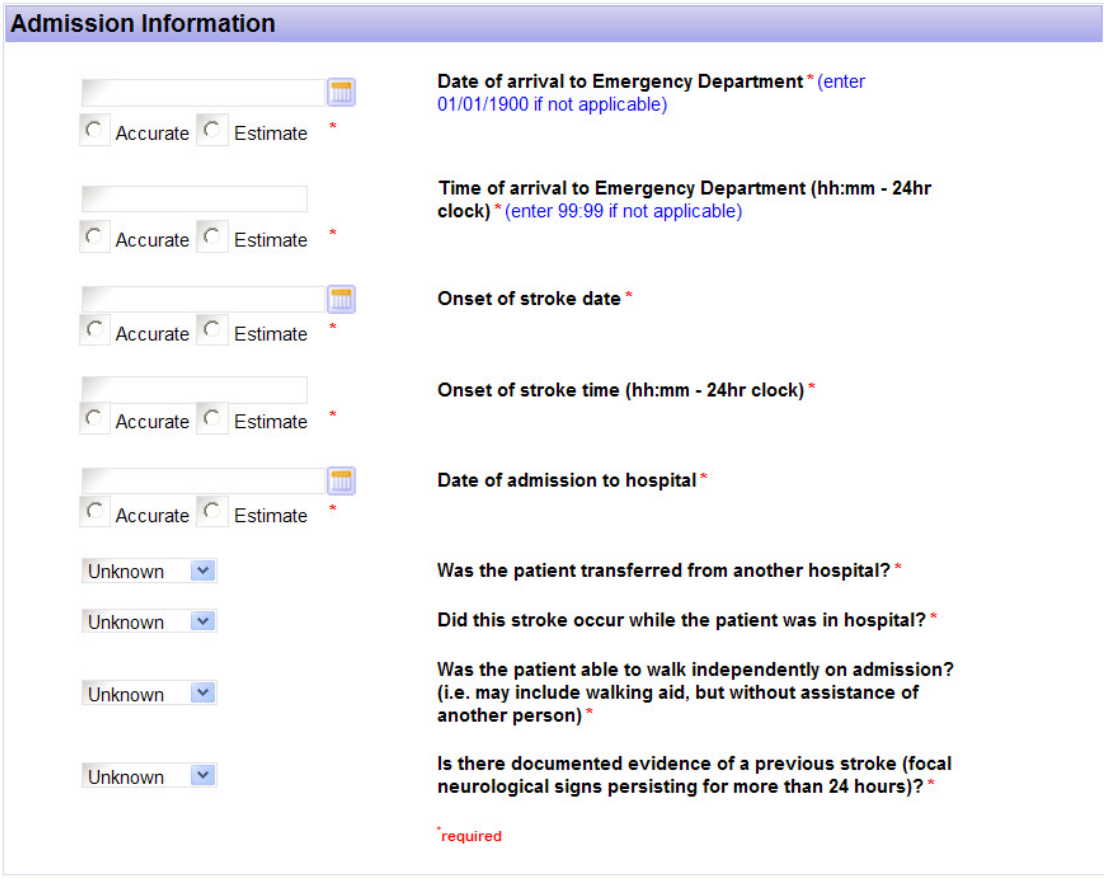
Table 11.1 Hints for Recording Time

Time	Record Time as:
Midnight (12:00 am)	23:59
Noon (12:00 pm)	12:00
12:15 am	00:15
6:00 am	06:00

Table 11.2 Guidelines for Estimating Times

Description of Time	Record Time as:
The middle of the night	03:00
Breakfast	08:00
Early morning	08:00
Morning	09:00
Late morning	10:00
Lunch	12:00
Midday or 12 Noon	12:00
Early afternoon	14:00
Afternoon or mid afternoon	15:00
Late afternoon	16:00
Dinner/Supper	18:00
Early evening	19:00
Evening	21:00
Late evening	22:00

Figure 11.1 Admission Information Section


Admission Information
Accurate Estimate *
Date of arrival to Emergency Department * (enter 01/01/1900 if not applicable)
Accurate Estimate *
Time of arrival to Emergency Department (hh:mm - 24hr clock) * (enter 99:99 if not applicable)
Accurate Estimate *
Onset of stroke date *
Accurate Estimate *
Onset of stroke time (hh:mm - 24hr clock) *
Accurate Estimate *
Date of admission to hospital *
Unknown
Was the patient transferred from another hospital? *
Unknown
Did this stroke occur while the patient was in hospital? *
Unknown
Was the patient able to walk independently on admission? (i.e. may include walking aid, but without assistance of another person) *
Unknown
Is there documented evidence of a previous stroke (focal neurological signs persisting for more than 24 hours)? *
*required

Clinical Information (Figure 11.2)

1. Select the appropriate option from the drop down list for each of the following questions/fields:
   - *Was the patient treated in a Stroke Unit at any time during their stay?*
   - *Type of Stroke*

     Important Note: If *Type of Stroke* selected is *Ischaemic* the following question will appear.
   - *If an Ischaemic stroke, did the patient receive intravenous Thrombolysis (tPA)?*
   - *Cause of Stroke*

Important Note: modified TOAST criteria should be applied to determine if the *Cause of Stroke* is 'known' or 'unknown'.

Cause would be 'Known' if:	Cause would be 'Unknown' if:
large-artery atherosclerosis	cause cannot be identified
cardioembolism	two potential causes are present but it is unknown which is likely to be the cause.
small-vessel occlusion	
stroke of other determined etiology - elicit drug use - metabolic disorder - intervention/post-operative	evaluation is incomplete

2. **ICD10 - Principal Diagnosis:** Select a stroke ICD10 code from the Principal Diagnosis drop down list. If the Principal Diagnosis is not stroke or the stroke codes provided do not match the Medical Record Principal Diagnosis, then enter this code directly into the Principal Diagnosis box.

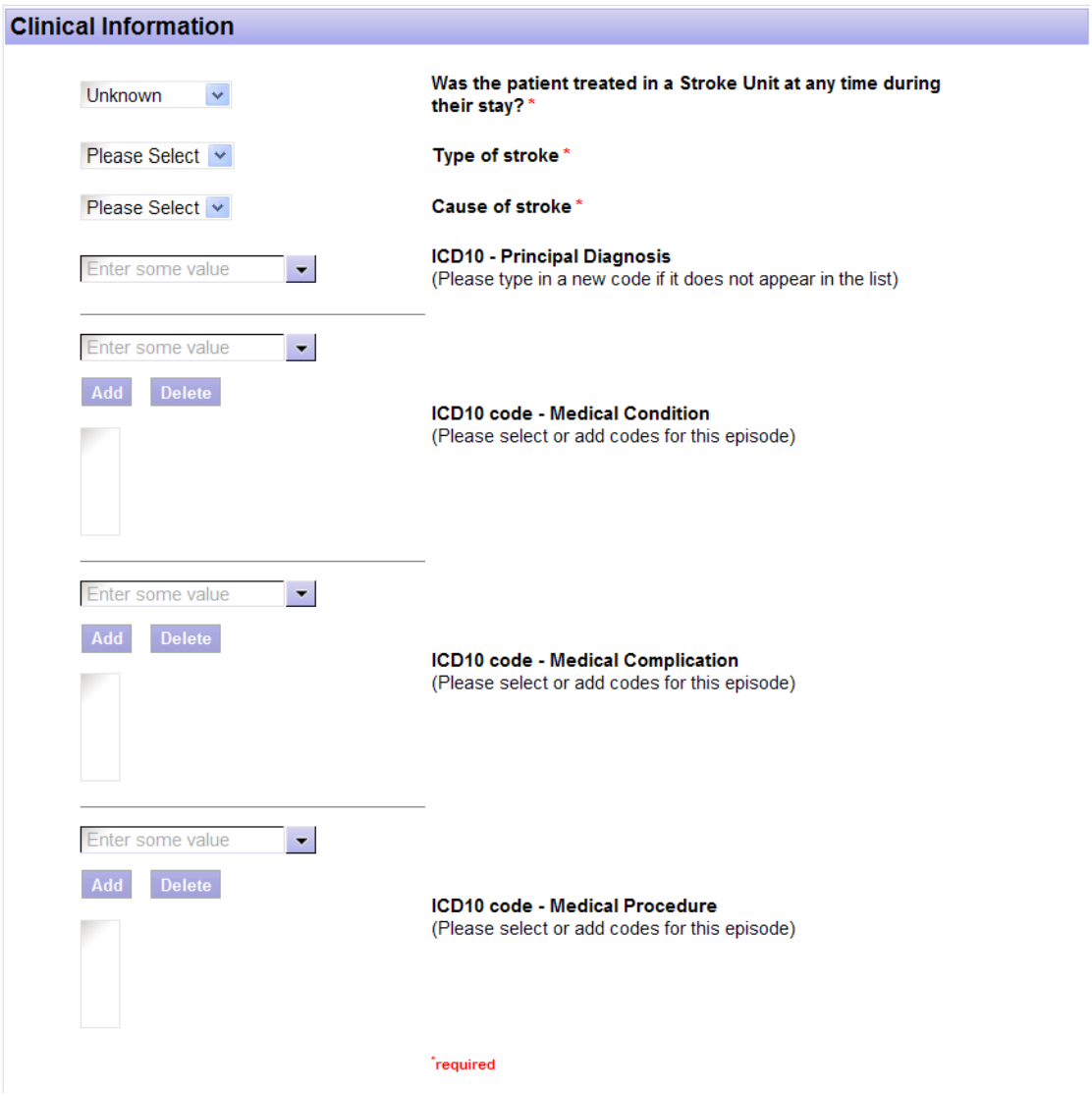
   This text box will only permit valid ICD10 codes to be entered according to the following format: ANN{.N[N]} (refer to the Data Dictionary for details).

3. **ICD10 code - Medical Condition:** Enter an ICD10 code for the Medical Condition/s that is/are available from the Medical Record into the drop down list, the system will attempt to auto-complete the code. After entering each code click the **Add** button before entering the next Medical Condition ICD10 code. Clicking the **Add** button will append the code to the list box under the **Add** button.

4. **ICD10 code – Medical Complication:** Enter an ICD10 code for the Medical Complication/s that is/are available from the Medical Record into the drop down list, the system will attempt to auto-complete the code. After entering each code click the **Add** button before entering the next Medical Complication ICD10 code. Clicking the **Add** button will append the code to the list box under the **Add** button.

5. **ICD10 code – Medical Procedure:** Enter an ICD10 code for the Medical Procedure/s that is/are available from the Medical Record or hospital records into the drop down list, the system will attempt to auto-complete the code. After entering each code click the **Add** button before entering the next Medical Procedure ICD10 code. Clicking the **Add** button will append the code to the list box under the **Add** button.

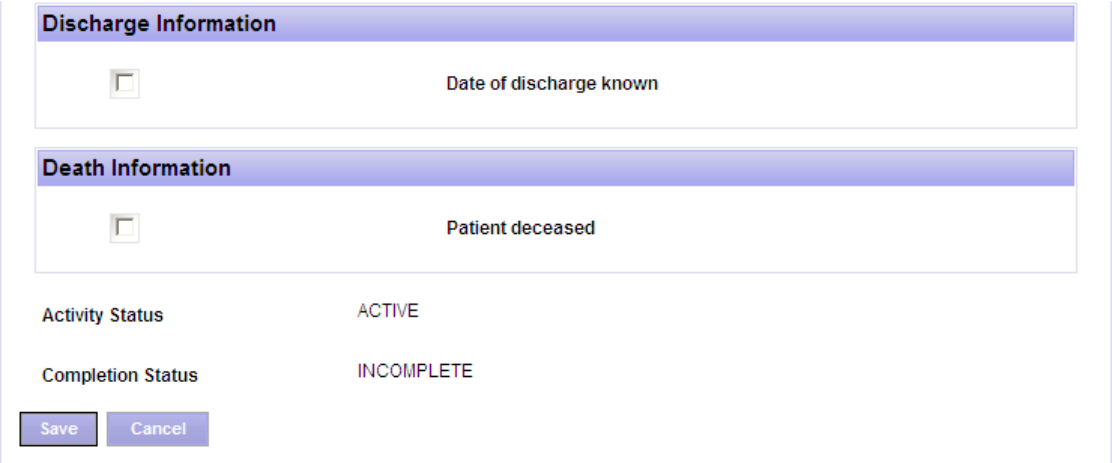
Figure 11.2 Clinical Information Section


Clinical Information
Unknown
Was the patient treated in a Stroke Unit at any time during their stay? *
Please Select
Type of stroke *
Please Select
Cause of stroke *
Enter some value
ICD10 - Principal Diagnosis
(Please type in a new code if it does not appear in the list)
Enter some value
Add
Delete
ICD10 code - Medical Condition
(Please select or add codes for this episode)
Enter some value
Add
Delete
ICD10 code - Medical Complication
(Please select or add codes for this episode)
Enter some value
Add
Delete
ICD10 code - Medical Procedure
(Please select or add codes for this episode)
*required

Important Note: To remove a code from the list box below the **Add** button, select the code in the list box then click the **Delete** button.

Discharge Information

Figure 11.3 Discharge Information and Death Information Section



1. Click the *Date of discharge known* tick box if applicable. This will expand the **Discharge Information** section to display additional data entry fields (Figure 11.4).
2. Type in or use the calendar to select the *Date of discharge* and indicate whether the date is *Accurate* or an *Estimate* by clicking one of the corresponding radio buttons.

Important Note: If **patient died in hospital** *Date of discharge* should be the same as *Date of death*

3. Select the appropriate option from the drop down list for each of the following questions/fields:
   - *Discharge destination/mode (Table 11.3).*

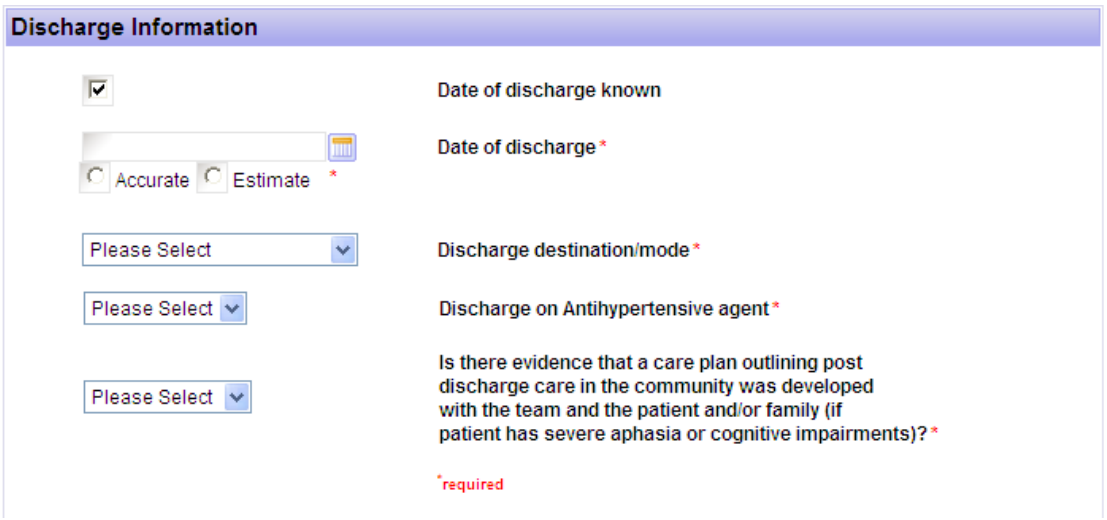
   Important Note: The following two questions below will not appear if "*Died in hospital"* is selected as the *Discharge destination/mode* .
   - *Discharge on Antihypertensive agent*.
   - *Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family*?

Table 11.3 Discharge Destination/Mode List

Discharge Destination/Mode	Explanation of where the patient is discharged to:
Hospital	A different acute hospital or palliative care hospital
Rehabilitation (inpatient)	Rehabilitation unit/ hospital
Low level Residential care	Aged Care Hostel/ Special accommodation facility
High level Residential care	Nursing Home/ Aged Care facility; Note private palliative care nursing homes may also be classified under this category.
Home with supports	Living at home entirely alone
Home without supports	Living at home with some support structure
Transitional care service	A community-based health care service program
Died in Hospital	Died while in hospital
Other	Include welfare institution such as prisons, group homes e.g. boarding houses providing primarily welfare services.

Important Note: If *Died in hospital* is selected, the **Death Information** section must be completed.

Figure 11.4 Discharge Information Section (Expanded)


Discharge Information
Date of discharge known
Date of discharge *
Accurate
Estimate
*
Please Select
Discharge destination/mode *
Please Select
Discharge on Antihypertensive agent *
Please Select
Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)? *
*required

Death Information

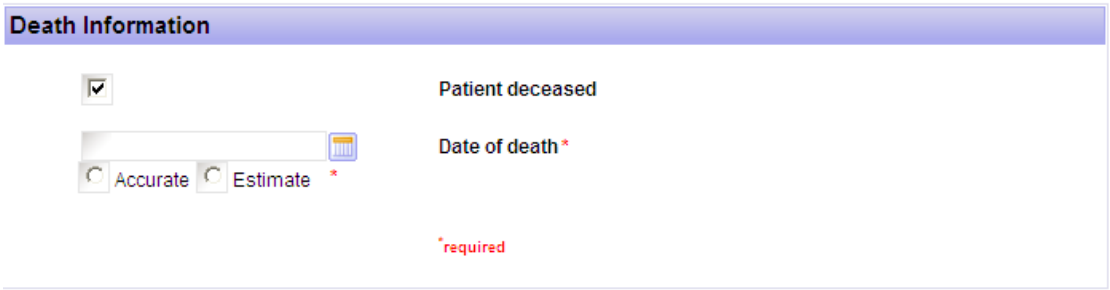
1. Click the *Patient deceased* box if applicable. This will expand the **Death Information** section to display additional data entry fields (Figure 11.5).
2. Type in or use the calendar to select the *Date of death* and indicate whether the date is *Accurate* or an *Estimate* by clicking one of the corresponding radio buttons.

Important Note:

- If a patient is discharged from hospital but dies before data entry is complete, or if a patient is known to have died within 3 months of admission, please enter death data so that we do not contact family members and request for them to complete a follow-up questionnaire.
- The AuSCR Database includes logic to minimise data entry errors (e.g. Date of death cannot occur before Date of birth).
- If you did not complete **any of the required fields** in the admission screen, when you click save, an error message will alert you, however, **if you ignore it and exit the screen none of the information will be saved.**
- Once all of the data has been entered, click the **Save** button at the bottom of the page to save the Episode information. An **Admission Information** page will be displayed showing all information entered for the episode. If the episode is completed it must be locked by clicking the **Complete and Lock** button located at the bottom of the page (See section 13 for further information).

Important Note: When **Completion Status** shows "Incomplete" it means you can re-enter the episode at a later stage and make changes to complete the data collection.

Figure 11.5 Death Information



12 Searching for a Patient/Edit Patient

Important Note: Users can only see patients from their own hospital

To search for a patient:

1. Click the **Search Patient** button on the navigation menu and the **Patient Search** page will be displayed (Figure 12.1). This page displays the list of existing patients, and their corresponding episode/s, sorted by the date when the patient record was last updated (the most recently updated record is listed first).
2. Search for patients by entering the *First Name*, *Last Name* or *MRN* (or a combination of these) into the search text boxes at the top of the screen and clicking the **Search** button.
3. Click the page numbers or arrows at the top of the Patient List to scroll between the pages of patients as follows:

   << << to move to the first page

   << to move to the previous page

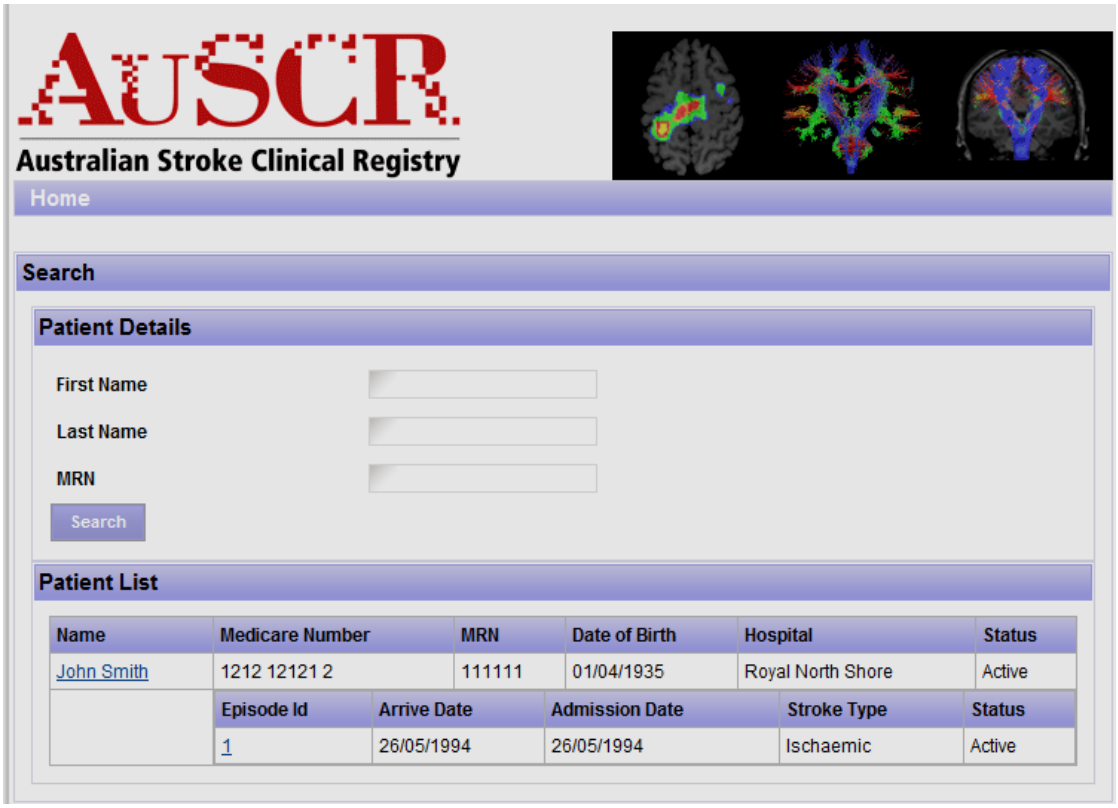
   >> to move to the next page

   >> >> to move to the last page
4. Click on the hyperlinked **Patient Name** to view the patient details. To edit the patient details click the **Edit** button at the bottom of the page.
5. Click on the hyperlinked **Episode Id Number** to view the details of a specific episode. To edit an episode click the **Edit** button at the bottom of the page.

Important Note:

- You will only be able to search for and see patients associated with your hospital
- Episode numbers are not sequential by date of episode of stroke but by date of data entry.
- If the episode is locked, the episode cannot be edited and the **Edit** button will not appear. A request has to be made to the AuSCR office by email to admin@auscr.com.au to unlock the episode so the episode can be edited

Figure 12.1 Patient Search Page



13 Locking an Episode

The AuSCR Database allows users to lock an episode and hence prevent it from being edited. **All episodes must be locked once completed.**

To lock an episode:

1. Search for the patient with the episode to be locked.
2. View the episode to be locked by clicking on the hyperlinked Episode Id.
3. Click the **Complete and Lock** button located at the bottom of the page.
4. This will change the Completion Status of the episode to 'COMPLETE' and it will no longer be able to be edited.

Important Note: Only a Superuser or Project Team Administrator can unlock a locked (i.e. 'Complete') episode.

14 Request Deletion of an Episode

All users are able to request the deletion of an episode, however this action needs to be confirmed by a Superuser or Project Team Administrator before the record is actually deleted. To request the deletion of an episode:

1. Search for the patient with the episode to be deleted in the “Search Screen” using the Patient list.
2. View the episode to be deleted by clicking on the hyperlinked Episode Id.
3. Click the **Delete** button located at the bottom of the page.
4. This will change the Activity Status of the episode to ‘INACTIVE’ and it will no longer be able to be edited and used by Hospital Users or Hospital Administrators
5. The patient episode requested for deletion will automatically be added into the **Delete Episode List,** accessible only to Superusers and Project Team Administrators at the AuSCR office.
6. The Superuser or Project Team Administrator from the AuSCR office will perform the actual deletion using the **Delete Episode List,** during scheduled data management processes

Important Note: Actual deletion can only be performed by a Superuser or Project Team Administrator from the AuSCR office. **Once deleted it cannot be reversed**.

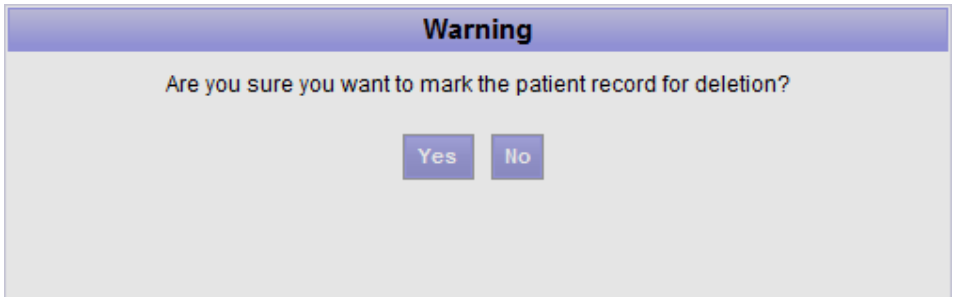
15 Request Deletion of a Patient Record

All users are able to request the deletion of a patient record, however this action needs to be confirmed by a Superuser or Project Team Administrator before the record is actually deleted. To request the deletion of a patient episode:

1. Search for the patient to be deleted.
2. View the patient to be deleted by clicking on the hyperlinked Name.
3. Click the **Delete** button – a warning panel will appear (Figure 15.1).
4. Click the **Yes** button to confirm the deletion (or the **No** button to cancel the deletion).
5. If the **Yes** button is selected, the Status of the patient will now appear as ‘Inactive’.
6. The patient episode requested for deletion will automatically be added into the **Delete Deletion List,** accessible only to Superusers and Project Team Administrators at the AuSCR office.
7. The Superuser or Project Team Administrator from the AuSCR office will perform the actual deletion using the **Delete Deletion List,** during scheduled data management processes

Important Note: Actual deletion can only be performed by a Superuser or Project Team Administrator. **Deleting a patient will delete all associated episodes linked to the patient. Once deleted it cannot be reversed.**

Figure 15.1 Delete Patient Warning



16 Request to Opt Out data from AuSCR

A patient who has been added to the AuSCR Database may request to 'opt out' or have certain data elements removed e.g. their contact information. AuSCR Hospital Users need to request to have these data removed by AuSCR office staff on behalf of the patient. ***Hospital staff cannot opt out or remove data from the AuSCR database.***

The **opt out request** occurs in two stages; the request by the Hospital User, followed by the confirmation by the Superuser or Project Team Administrator.

To request data to be opted out for a patient:

1. Search for the patient to be opted out.
2. Click the hyperlinked Name for the patient to be opted out and the **Patient Information** screen will be displayed.
3. Click the **Opt Out** button at the bottom of the page and the **Opt Out** page will be displayed (Figure 16.1).
4. Select the corresponding radio buttons of the item/s the patient/guardian or next or kin has requested to opt out.
5. Add any comments to describe why the data are being opted out.
6. Click the **Save** button and a warning panel will appear (Figure 16.2).
7. Click the **Yes** button to confirm the request (or the **No** button to cancel the request). It will bring you to the Opt Out information save page (Figure 16.3).
8. The request will automatically be added to the **Opt Out List,** accessible only to Superuser and Project Team Administrator at the AuSCR office.
9. The Superuser or Project Team Administrator from the AuSCR office will perform the actual opt out using the **Opt Out List,** during scheduled data management processes

Remember:

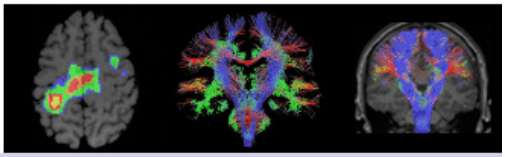
- If you have made a mistake, or incorrectly entered a patient who did not have a stroke, then you should **Delete** this case, and not request for this person to be Opted-Out.
- If a patient is happy to have their details in the AuSCR Database, however does not want to be contacted again at follow-up (post-discharge), you should click the **Do not Contact Patient at Follow Up** box which appears beneath the discharge information screen, and not request for this person to be Opted-Out.

Important Note: Actual opt out can only be performed by a Superuser or Project Team Administrator. **Opt Out once confirmed cannot be reversed.**

Please re-read section 4, the *Opt Out Consent Model*, before proceeding with an opt-out request.

Figure 16.1 Opt Out Page

AuSCR
Australian Stroke Clinical Registry



Home

Comments:

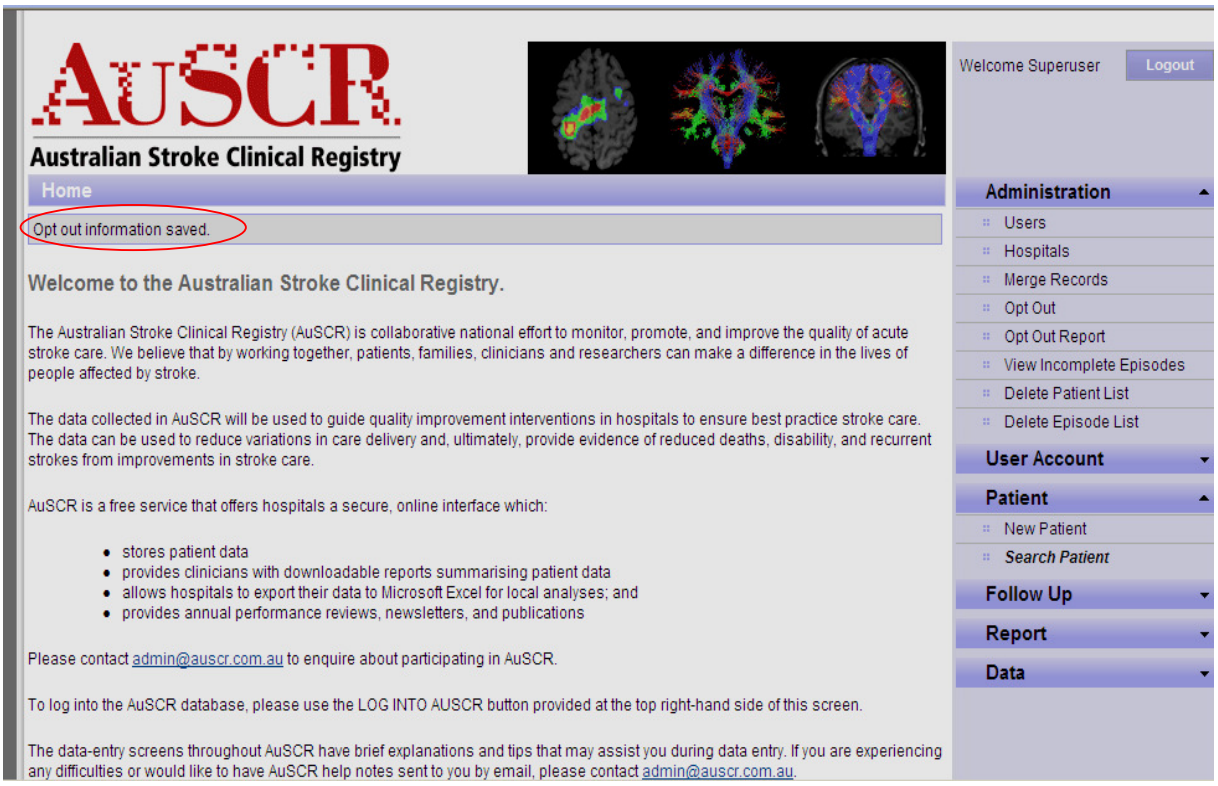
Select All ☐ Do not contact for follow-up ☐

☐ First Name	☐ Last Name	☐ Date of Birth	☐ Medicare No	☐ Title
☐ Gender	☐ Phone Number	☐ Mobile Number	☐ Aboriginal/Torres St. Islander	☐ Country of Birth
☐ Language Spoken	☐ Interpreter Needed			
☐ Address/Mailing Address	☐ Address/Address Type	☐ Address/Street Address	☐ Address/Suburb	☐ Address/State
☐ Address/Postcode	☐ Address/Country			
☐ Contacts/First Name	☐ Contacts/Last Name	☐ Contacts/Phone Number	☐ Contacts/Mobile Number	☐ Contacts/Relationship
☐ Contacts/Address Type	☐ Contacts/Address	☐ Contacts/Suburb	☐ Contacts/State	☐ Contacts/Postcode
☐ Contacts/Country				
☐ Date of arrival to emergency department	☐ Time of arrival to emergency department	☐ Onset of stroke date	☐ Onset of stroke time	☐ Date of admission to hospital
☐ Was the patient transferred from another hospital?	☐ Did this stroke occur while the patient was in hospital?	☐ Was the patient able to walk independently on admission?	☐ Is there documented evidence of a previous stroke?	☐ Was the patient treated in a Stroke Unit at any time during their stay?
☐ Type of stroke	☐ Did the patient receive Intravenous Thrombolysis?	☐ Cause of stroke		
☐ ICD10 code - Diagnosis	☐ ICD10 code - Medical Condition	☐ ICD10 code - Complications	☐ ICD10 code - Procedures	
☐ Date of discharge known	☐ Date of discharge	☐ Discharge destination/mode	☐ Discharge on Antihypertensive agent	☐ Is there evidence that a care plan outlining post discharge care
☐ Deceased	☐ Date of death			

Save Cancel

Figure 16.2 Opt Out Warning

Figure 16.3 Opt Out information saved


AuSCR
Australian Stroke Clinical Registry
Welcome Superuser
Logout
Home
Opt out information saved.
Welcome to the Australian Stroke Clinical Registry.
The Australian Stroke Clinical Registry (AuSCR) is collaborative national effort to monitor, promote, and improve the quality of acute stroke care. We believe that by working together, patients, families, clinicians and researchers can make a difference in the lives of people affected by stroke.
The data collected in AuSCR will be used to guide quality improvement interventions in hospitals to ensure best practice stroke care. The data can be used to reduce variations in care delivery and, ultimately, provide evidence of reduced deaths, disability, and recurrent strokes from improvements in stroke care.
AuSCR is a free service that offers hospitals a secure, online interface which:
stores patient data
provides clinicians with downloadable reports summarising patient data
allows hospitals to export their data to Microsoft Excel for local analyses; and
provides annual performance reviews, newsletters, and publications
Please contact admin@auscr.com.au to enquire about participating in AuSCR.
To log into the AuSCR database, please use the LOG INTO AUSCR button provided at the top right-hand side of this screen.
The data-entry screens throughout AuSCR have brief explanations and tips that may assist you during data entry. If you are experiencing any difficulties or would like to have AuSCR help notes sent to you by email, please contact admin@auscr.com.au.
Administration
Users
Hospitals
Merge Records
Opt Out
Opt Out Report
View Incomplete Episodes
Delete Patient List
Delete Episode List
User Account
Patient
New Patient
Search Patient
Follow Up
Report
Data

17 AuSCR Acute Data Collection Form

The Acute Data Collection Form is a hard copy of the AuSCR Database

Acute Data Collection Form (See Attachment 3) is available for:

- hospitals that are not entering data directly from the medical record into the AuSCR Database or
- hospitals experiencing technical difficulties using the AuSCR Database
- hospitals that do not have the capacity to enter data into the AuSCR Database.

Obtaining Acute Data Collection Forms

Forms can be obtained by contacting the AuSCR office by:

- email admin@auscr.com.au or telephone (02) 9993 4592. The AuSCR office can send the forms to you:
  - by email as a PDF document
  - by mail – when contacting the office provide a name and mailing address where the forms can be sent along with the number of forms required.
- Downloaded directly from the Database from the New Patient screen.

To download a copy of the Acute Data Collection form

- Log in to the Database
- Click the **New Patient** button on the navigation menu and the **New Patient** page will be displayed (Figure 17.1).
- Click on the hyperlinked **Download paper-based hospital data form**
- The Acute Data Collection form will be displayed which can now be printed.

Using the Acute Data Collection Form

- The form can be filled out on the ward during the hospital stay.
- The form should be checked at patient discharge and any missing data entered.
- The person responsible should sign and date the completed form.
- Once the form has been completed, the data can be entered into the AuSCR Database or it can be sent to the AuSCR office for data entry.
- "Good clinical practice" guidelines must be used in completing the forms. (NHMRC National Statement with TGA annotation /ICHGCP CPMP/135/95E6)
- Examples of both a correctly completed and a poorly completed Forms are attached (Attachment 3a and 3b).

Completing the Acute Data Collection Form

- Write neatly and legibly with black ink;
- Write Patient Name, Date of Birth, and Hospital name at the top of each page of the form (this will ensure that the record remains intact, even if faxed as separate pieces of paper);
- All patient information details must be completed with as much information as you can obtain. This is to assist in follow- up of the patient at 3-6 months.
- Mandatory questions are marked with an asterisk (*). These questions must be completed;

- If the information is not available, write the reason next to the question (e.g. to be obtained later, not available);
- With estimated or unspecified times and dates, use the rules for estimating times and dates that are outlined in the data dictionary;
- If you are using the hospital label and the name of the hospital is not printed on the label, please ensure your *Hospital Name* is entered in the box provided;
- Some hospital labels do not indicate Medicare numbers, MRN or DOB next to the numbers. If this is the case please complete the MRN and DOB box on the form.

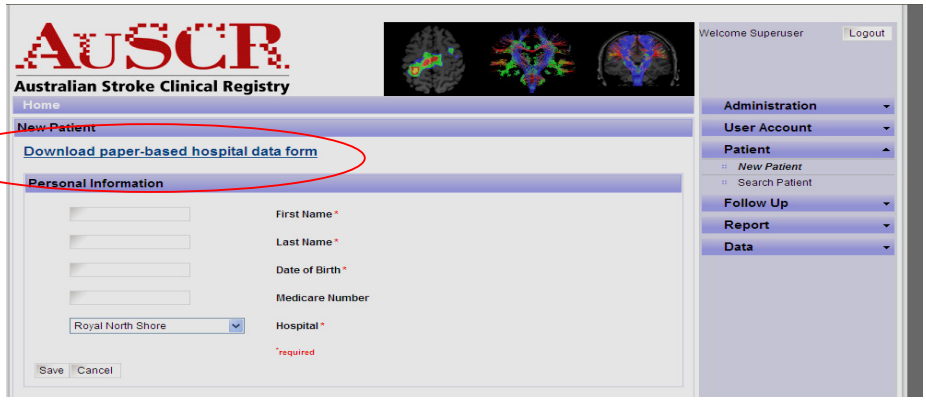
Correction of errors

- If an error is made when completing the form, please cross out using a single line, place the correct information next to or above the correction; initial and date the change;
- Do not use white out.

Sending completed forms to the AuSCR office

- You must contact the AuSCR office by email admin@auscr.com.au or telephone (02) 9993 4592 to inform them that you are sending them completed patient forms
- Completed forms can be sent to the AuSCR office by:
  - **Secure Fax: (02) 8507 2531 (only for confidential information)**
  - Scan and email to admin@auscr.com.au
  - Mail: AuSCR Project Office
    PO Box M201
    Missenden Road
    SYDNEY NSW 2050

Figure 17.1 Download Acute Data Collection Form



18 Downloadable Reports

Individual, pre-specified hospital reports are available to all hospital users via the AuSCR Database. The reports may be generated at anytime and use the current data available in the AuSCR Database. Therefore, data in these reports have not been verified or checked by the AuSCR office and are for internal use only (Table 18.1). The downloadable reports will provide summary data for the date range selected and are provided in tables and graphs for your convenience. These tables and graphs will include results from your hospital, as well as a summary estimate from all the cases entered from all participating sites.

The Hospital Administrator also has the ability to export your hospital data into an excel spreadsheet so you can run your own data analyses. These data will also include any unlocked cases (refer to section 19).

To access hospital reports:

1. Click the **Report** button on the navigation menu.
2. Click the **Reports** button on the navigation menu and the **Select Report** page will be displayed (Figure 18.1).
3. Select the *Report Type* from the drop down list.
4. Type in or use the calendar to select the *Start Date* for the report.
5. Type in or use the calendar to select the *End Date* for the report.
6. Click the **Generate Report** button
7. A dialogue box will open with an option to open or save the chosen Report (Figure 18.2)
8. “Open” option will open the chosen Report for viewing and saving can be done later
9. “Save” option will allow you to save the chosen Report to a folder in your computer.

Important Note: If there is an error a **new error window** will appear. **Close t**he new error window and go back to the original window to fix your errors.

Additional detailed annual report of verified data and case mix adjustments including follow-up data, with national and state comparisons will be provided by the AuSCR Management Team.

Table 18.1 Reports Table

Pre- Specified Reports Available
Patient Episode Totals
Characteristic of Patients
Age-group Profiles
Summary Age Data
Destination on Discharge
Summary of Discharge data
Length of Stay
Processes of Hospital Care
Stroke Type by Age
Stroke Type by Gender
Patients per Month

Figure 18.1 Reports Page

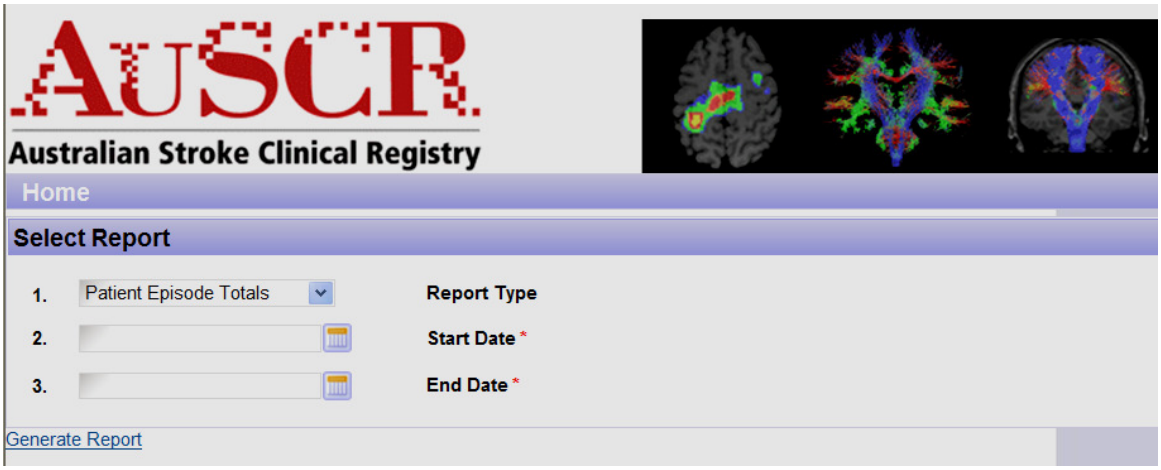
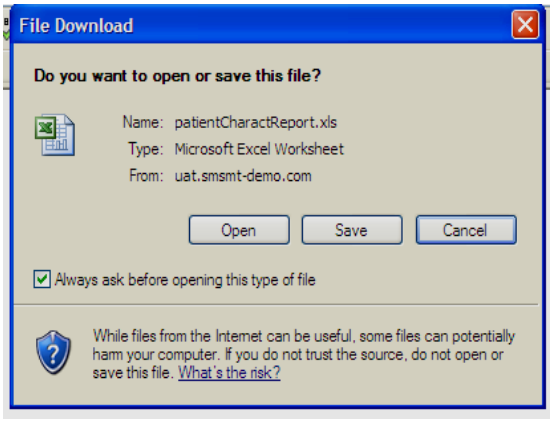


Figure 18.2 Report Dialogue Box


File Download
Do you want to open or save this file?
Name: patientCharactReport.xls
Type: Microsoft Excel Worksheet
From: uat.smsmt-demo.com
Open
Save
Cancel
Always ask before opening this type of file
While files from the Internet can be useful, some files can potentially harm your computer. If you do not trust the source, do not open or save this file. What's the risk?

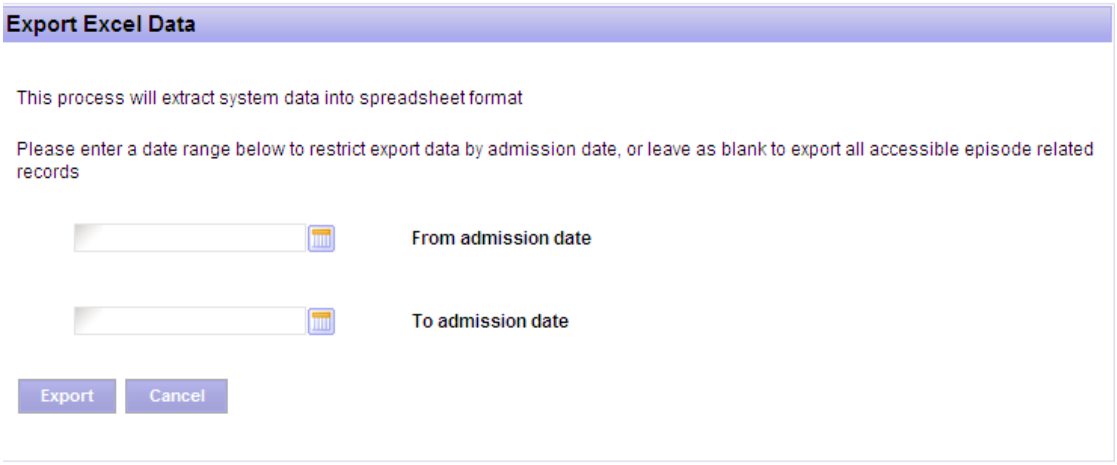
19 Data Export function (Hospital Administrator Only)

The AuSCR Database has a data export function. This function allows for the export of the "raw" data directly entered by your hospital for the date range selected. The "raw" data are provided in an Excel spreadsheet and can be manipulated for internal hospital reporting as desired. **Outside of the date range that AuSCR office has verified the data, it is your hospital's responsibility to check and clean the "raw" data**.

To export data:

1. Click the **Data** button on the navigation menu.
2. Click the **Export Excel** button on the navigation menu
3. The **Export Excel Data** screen will be displayed (see Figure 19.1).
4. Type in or use the calendar to select the date range desired.
5. Click the **Export** button
6. A dialogue box will open with an option to open or save the file
7. Clicking the **Open** button will open the file for viewing and saving.
8. Clicking the **Save** button will allow you to save the file to a folder in your computer

Figure 19.1 Data Export.


Export Excel Data
This process will extract system data into spreadsheet format
Please enter a date range below to restrict export data by admission date, or leave as blank to export all accessible episode related records
From admission date
To admission date
Export
Cancel

Important Note: The data will be exported to an Excel spreadsheet with a series of worksheets for some of the variables from the Database (i.e. hospital users only have the acute hospital data available for export). These worksheets include several unique (numeric) identifiers that can be linked to a patient. ***Unfortunately, the unique identifiers for a patient (person ID and patient record ID) are not always reported on each worksheet, so care is needed if wanting to link data between one worksheet and another.*** The system was designed this way since patients may have multiple admissions to the same hospital for different stroke events which are then eligible to be recorded as a different episode of care. Patients may also go to different hospitals. To enable an individual patient to be tracked in the AuSCR Database each individual is assigned a unique Person ID, then for a particular hospital they will have a Patient ID created; and each episode of care will also generate a unique Episode ID. In addition, for each contact list for a patient, a Contact ID will be created e.g. Emergency, Alternate, and General Practitioner. The relationships between the worksheets and the IDs available in each worksheet are summarised in the following table:

Worksheet	Linked Worksheet	Link
Hospital	Patient Record	Hospital Id
Hospital	Follow Up Patient	Hospital Id
Person	Patient Record	Person Id
Person	Follow Up Patient	Person Id
Patient Record	Patient Address	Patient Record Id
Patient Record	Patient Contact	Emergency Contact Id; Alternate Contact Id; GP Contact Id
Follow Up Patient	Follow Up Patient Address	Follow Up Patient Id
Follow Up Patient	Follow Up Patient Contact	Emergency Contact Id; Alternate Contact Id; GP Contact Id
Follow Up Patient	Follow Up Questionnaire	Follow Up Id

20 Importing Data

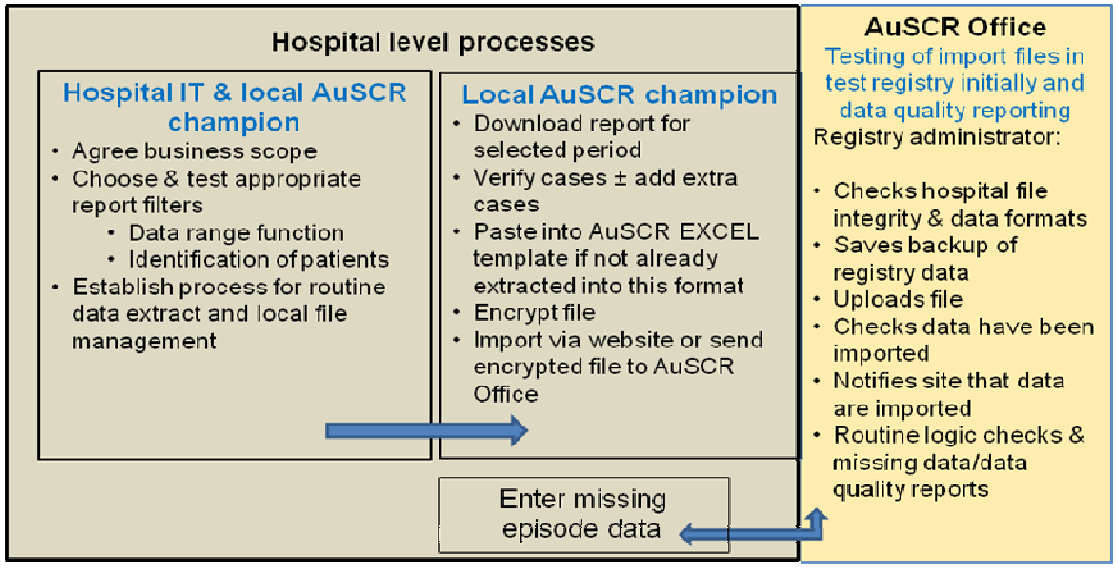
The AuSCR Database has some options available for hospitals that would like to directly import data into the system. An optional import data Excel-formatted template can be downloaded from the AuSCR Database and used by hospitals to upload data and avoid manual data entry which may also help to reduce systematic data entry errors, e.g. spelling of name, etc. This was developed to overcome the issues of variability in hospital information technology systems. We have also developed a web-service as another option for hospital staff who would like to upload data from their patient administrative systems into the AuSCR Database.

Nevertheless, there are risks and pitfalls when data are imported from one system to another. For example, careful selection of filters is required to ensure only eligible patients (e.g., new patients not already the system who have confirmed stroke or TIA) are entered into the AuSCR Database. Therefore, at this stage, only AuSCR office Superusers and Project Team Administrators have the authorisation

to import data into the system from a spreadsheet. Integration of web-services is more complicated which will allow for direct streaming of data into the system. Regardless of which option is nominated, local executive and IT Support will be needed to establish the best method of extracting relevant data from your hospital systems.

The AuSCR office staff will work with your local Informational Technology department to assess the best solution for importing data from your systems. By enlisting the support of local IT Infrastructure and Resources the AuSCR Hospital User can request an extract of data from the local Patient Administration System that can be imported directly into the AuSCR Database via the Internet. The local Hospital User can choose to import all data or only a portion of the data. The Hospital User / local AuSCR Champion and or Principle Investigator can choose what data are to be imported and what data are to be manually entered. At all stages, security of the data is ensured. A summary of the processes for establishing and using the import data options is outlined below in Figure 20.1.

Figure 20.1 Summary of the processes for establishing and using import data solutions for AuSCR.


Hospital level processes
Hospital IT & local AuSCR champion
Agree business scope
Choose & test appropriate report filters
Data range function
Identification of patients
Establish process for routine data extract and local file management
Local AuSCR champion
Download report for selected period
Verify cases ± add extra cases
Paste into AuSCR EXCEL template if not already extracted into this format
Encrypt file
Import via website or send encrypted file to AuSCR Office
Enter missing episode data
AuSCR Office
Testing of import files in test registry initially and data quality reporting
Registry administrator:
Checks hospital file integrity & data formats
Saves backup of registry data
Uploads file
Checks data have been imported
Notifies site that data are imported
Routine logic checks & missing data/data quality reports

Setting up

Initially clinicians need to contact the appropriate local business managers and IT department managers to discuss the IT requirements. Resources to establish hospital extracts needs to be addressed locally, and can be justified in terms of reducing clinician time needed for data entry.

AuSCR office will provide supporting technical documentation outlining the specific data requirements for the AuSCR Import process.

Since it is important that all patients with stroke admitted to a hospital or who experience an in-patient stroke are entered in the AuSCR Database, careful selection of filters to create a hospital extract for data importing is needed. For example, this might be based on key words in a provisional diagnosis and/or

limiting the filter for particular Medical Units. No set of filters will be perfect, so some manual scrutiny and assessing various options might be needed. Once the best fit is found for ensuring the greatest coverage of eligible patients the extract can be finalised which can then be used to populate the AuSCR Import Template (see below).

AuSCR office will coordinate with local IT resources to test the import file and feedback the necessary specifications to facilitate the data import.

To maintain Information Security / Privacy during the initial stages of testing the Import file is transferred via email to the AuSCR office. This file is encrypted to secure the information. (Refer to Encrypting MS Excel Workbook version 2003 for transmitting Stroke Data to AuSCR section below). After testing is completed and a workable version of the Import File can be independently produced at the local hospital the hospital user can import the file directly into AuSCR.

Compatibility

To maximise compatibility a prespecified Microsoft Excel 2003 file can be downloaded from the AuSCR Database by a hospital user logged into AuSCR. This file is a formatted template for data import.

This template has several requirements for successful importing of data into AuSCR. Each coloumn has a specific data type or has a set of predefined values compatible with METeOR standards.

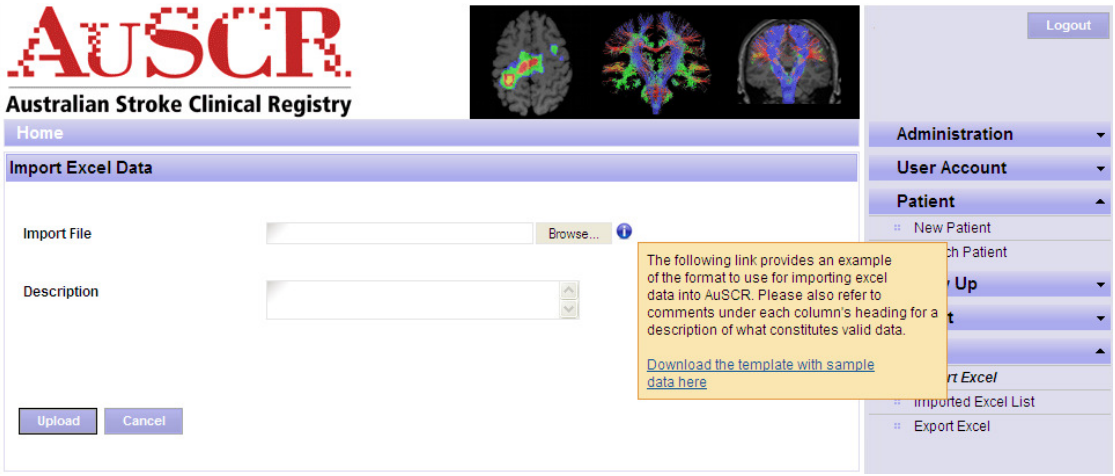
Mapping data from local Patient Administration System to the AuSCR template.

Some of the predefined coloumn values in the AuSCR template need to be mapped for successful data import. These mappings are compatible with MeTEOR standards which most hospitals already use in the Patient Administration System. AuSCR office staff will work directly with local technicians to ensure valid mapping of data from the local Patient Administration System.

To obtain the Import Template.

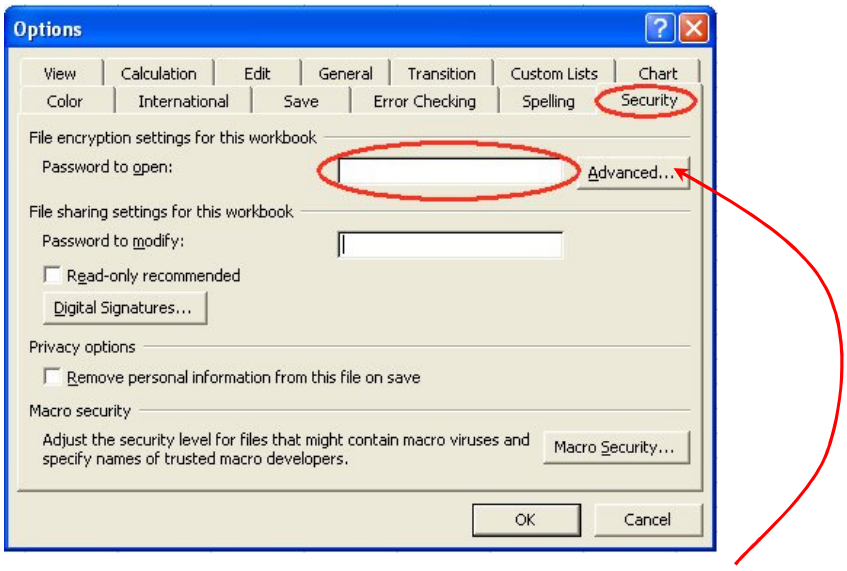
1. Click the **Data** button on the navigation menu.
2. Select **Import Excel** button on the navigation menu.
3. The **Import Excel Data** screen will be displayed.
4. To download the Import Template spreadsheet click the information icon:
5. In the yellow pop up message, click the “Download the template with sample data here” link.
6. The File Download dialogue box will pop up, click save to save the spreadsheet.

Figure 20.2 Import Excel Data Screen



Encrypting MS Excel Workbook version 2003 for transmitting Stroke Data to AuSCR.

1. Open the saved EXCEL file you wish to password protect, and click Tools / Options
2. This will open the "Options" screen click the Security tab.



3. Click the Advanced button to the right of the Password to open field.

Encryption Type
Choose an encryption type:
RC4, Microsoft Base Cryptographic Provider v1.0
RC4, Microsoft Base DSS and Diffie-Hellman Cryptographic Provider
RC4, Microsoft DH SChannel Cryptographic Provider
RC4, Microsoft Enhanced Cryptographic Provider v1.0
RC4, Microsoft Enhanced DSS and Diffie-Hellman Cryptographic Provider
RC4, Microsoft Enhanced RSA and AES Cryptographic Provider (Prototype)
RC4, Microsoft RSA SChannel Cryptographic Provider
RC4, Microsoft Strong Cryptographic Provider
Choose a key length:
128
Encrypt document properties
OK
Cancel

4. This will open the “Encryption Type” dialogue box.
5. Select “RC4, Microsoft Enhanced Cryptographic Provider v1.0” from the “Choose an encryption type” list.
6. Select “128” from the “Choose a key length:” field.
7. Ensure that “Encrypt document properties” is checked.
8. Click Ok button.
9. On the “Options” screen: enter a ***strong password*** (see below) into the “Password to open” field.
10. Click OK button.

Important Note: Strong password:

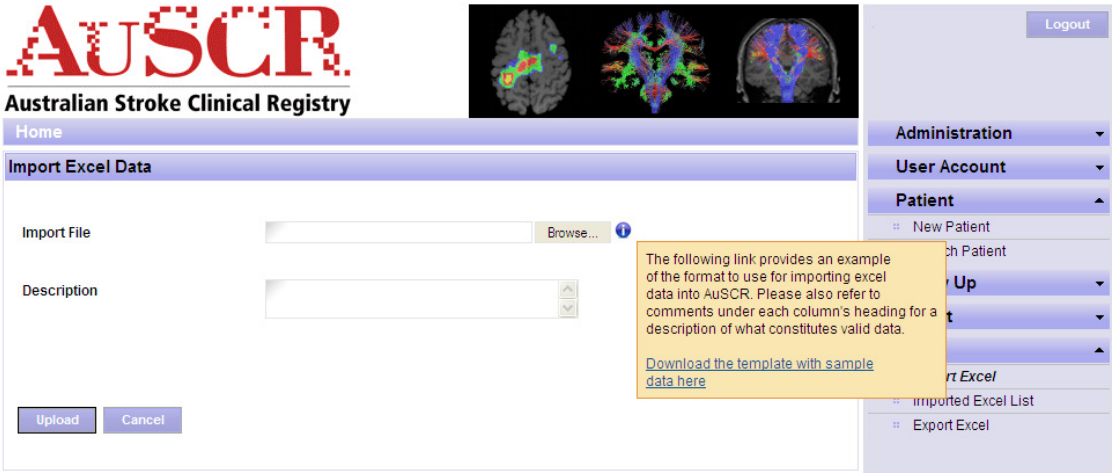
- Minimum of 10 characters.
- Complexity of characters, use of non alphabetical and numeric, mixed case characters.
- AuSCR Office will negotiate with user and send via email to the user.

Send your password protected file as an email attachment and clearly state your site ID and period that the data cover to admin@auscr.com.au.
Ensure that you also save a copy of each file in a local hospital computer directory set-up for AuSCR and give it a unique name that will ensure creating new hospital extract files that have overlapping/duplicate data are avoided. For example, the date range should be listed as part of the file name.

AuSCR Import Excel Data Screen

To Import Data:
Currently data is uploaded by AuSCR office staff; until a reliable version of the import file can be independently produced at the local hospital then a hospital user can import the file directly into AuSCR

1. Click the **Data** button on the navigation menu.
2. Select **Import Excel** button on the navigation menu.
3. The **Import Excel Data** screen will be displayed.
4. After copying data into the template.
5. Click the **Browse** button.
6. Select the Import Template from the “Choose File to Upload” dialogue box. Click open.
7. Click the **Upload** button.



Important Note: If there are any errors the Import Excel Data screen will show the message: "FAILED - Data was not uploaded!! Please fix above validation errors and try again." User can see which record was problematic and why.
When the import is successful the screen will indicate this to the user: "SUCCESS - Data was successfully uploaded"

21 Follow-up

Approximately three months after admission to hospital, patients will be followed up by AuSCR staff via telephone and/or postal questionnaire. They will be asked to complete questions about their current living circumstances and health status including questions about their quality of life. The EuroQol EQ5D is used for adults and the PedsQL for those aged less than 18 years to assess quality of life. At this time, the AuSCR project staff will again explain to each patient their right to opt out any or all information in the registry and/or their ability to refuse to participate in the follow-up survey.

22 Error screens

Occasionally, the system may encounter an error that it cannot handle. In these situations, please contact admin@auscr.com.au.

There are several errors that will not normally need intervention from the AuSCR admin. These are:

- **Optimistic Lock Exception** (Figure 22.1) - this occurs when more than one user tries to update the same record at the same time. The system prevents this occurring because data may be lost if simultaneous updates occur. If you encounter this error, you will have to navigate through the right menu and reapply your updates again.
- **Access Denied** - this occurs when the user tries to access a page that they do not have access to (Figure 22.2). If you encounter this error, you will have to navigate through the right menu and navigate to another screen that you do have access to. Contact AuSCR admin if you really need to revise your user access.

Figure 22.1 Optimistic Lock Exception

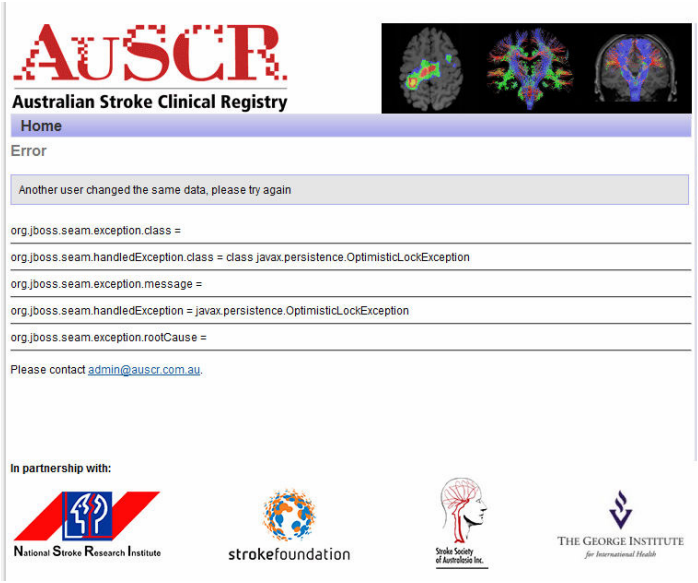
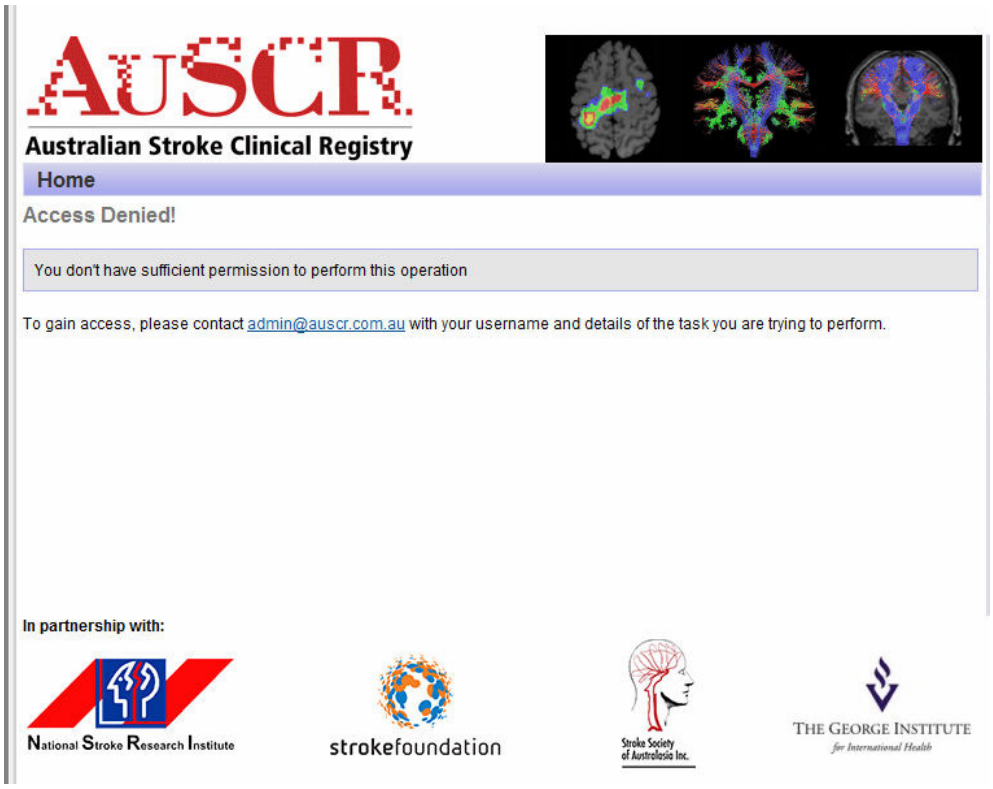


Figure 22.2 Access Denied


AuSCR
Australian Stroke Clinical Registry
Home
Access Denied!
You don't have sufficient permission to perform this operation
To gain access, please contact admin@auscr.com.au with your username and details of the task you are trying to perform.
In partnership with:
National Stroke Research Institute
strokefoundation
Stroke Society of Australasia Inc.
THE GEORGE INSTITUTE
for International Health

23 Quality Assurance Data Management Processes

The AuSCR Database has many in-built logic checks in place to prevent inaccurate information being entered. However, additional data checking processes are required to be undertaken by the AuSCR office at routine intervals. This will include:

- the AuSCR office running routine data queries which will identify missing data and data discrepancies. These reports will be sent to the hospital administrator/hospital user for verification prior to locking the patient episodes.
- cross referencing ICD10 discharge codes from the hospital patient administration system (database) with cases entered in AuSCR Database to ensure all eligible admission have been captured
- random medical record auditing by the AuSCR office following a pre arranged site visit may also be undertaken to assess the accuracy of data. The registry data collection processes and conformity with variable definitions will also be assessed during this site visit which is anticipated, in the first year of participation, when the first 50 cases have been entered and then bi-annually unless concerns about data quality have been identified.

24 Feedback

AuSCR is a new project and your feedback is valuable as this will assist in further improvements to the Database and registry processes and procedures.

AuSCR will be scheduling feedback one week following initial training and one month following commencement of data collection using a structured questionnaire.

As required, please email any other feedback to admin@auscr.com.au.

25 Frequently Asked Questions

What do I do if the same person is entered twice?

If you enter a new patient with the same *First Name*, *Last Name*, *Date of Birth* and *Medicare Number* as an existing patient, the system will automatically find the existing patient record and display their details for editing rather than creating a duplicate record for the same person.

If the same person is entered twice because incorrect data has been entered in one of the records, you can request that the incorrect record to be deleted following the steps outlined in section 15 of this manual.

What do I do if I don't know the ICD10 code?

The ICD10 codes must be obtained from the Medical Records department following completion of coding.

What do I do if there are no contact details?

Enter – "No fixed address", "Homeless" or "Nursing Home" in the **Suburb** field of the address (Refer to Data Dictionary).

What do I do if the patient is from overseas?

- All cases are to be included unless the patient chooses to "opt out".
- All data can be entered as usual.
- Record their temporary Australian contact details, as other address type.
- Record their usual home overseas as home address type.
- Select "Overseas" as the State/Territory. An overseas postcode can be entered if "Overseas" has been selected.

What do I do if I get an error message?

- Press "Print screen" on your keyboard to capture the error message displayed on your screen.
- Open a word document and paste it in. Write below it what happened prior to you getting the error message. Save it as an "error message – hospital name".
- Email the document as an attachment to admin@auscr.com.au

How do I obtain a password?

Each hospital will have a Hospital Administrator created by the AuSCR office. Your Hospital Administrator can issue you with a username and password. Once created, your username and password will be emailed to you.

How do I edit information in the AuSCR Database?

It is not possible to edit any errors or add anything to the Patient Information screen once you have pressed "SAVE"- this includes the Patient's Name, Date of Birth and Medicare Number. To edit this information, you should contact the AuSCR office, or delete this patient and start again with the correct information.

If you would like to edit the stroke episode details (such as date of stroke, date of arrival, or even type of stroke) you may do so at anytime up until you "lock" the episode. Once you have completed the corrections, you should save the episode, and then lock the episode (this will allow the person to be followed up in the community).

If you would like to edit the stroke episode details *after* you have locked the episode of care, you must contact the AuSCR office, who are able to *unlock* the episode for you to complete your editing. However, once completed you must lock this episode again to permit follow-up to occur.

There seems to be some questions missing for the patients who die in hospital.

The following two questions below will not appear if “Died in hospital” is selected as the Discharge destination/mode:

- *Discharge on Antihypertensive agent.*
- *Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family?*

If ‘died in hospital’ is selected, you must complete the Death Information that opens up in the webtool. You should also make sure that Date of discharge is the same as Date of death.

What to I do for people who go home and were not given an information sheet?

It may be that a person has been admitted and discharged without receiving an information sheet. It is important that *everyone* receives an information sheet, and so these patients must be contacted by letter following hospital discharge by their treating doctor to provide them with a copy of the Participant Information Sheet.

A sample copy of such a letter is attached in Attachment 6.

Appendix 1 Technical specifications for Import file data entry

Data Source

Commonly the data is sourced from the local Patient Admission System (PAS). A query is used to extract a cohort of stroke patients. This candidate list may contain non-stroke patients; the list may also miss stroke patients. If necessary a clinician would remove the inappropriate entries from the list and add the missing patient details. This needs to be formatted according to the following rules:

- Saved on a worksheet in a Microsoft Excel 2003 spreadsheet file.
- A template is available from the AuSCR Database by clicking the link in the main menu Data / Import Excel. Then click the information button and click the hyperlink: “Download the template with sample data here”.
- The name of the worksheet is mandatory “Data Import Form”
- The order of the coloumns is mandatory.
- The first row is assumed to be a header row.
- All data must be saved as text (including dates and numbers)
- All dates must be formatted as dd/mm/yyyy
- Each coloumn attribute has specific data type (text) or has a set of predefined values compatible with MeTEOR standards.

Data Entry Constraints

The system requires, as a minimum, the following data:

1. It is recommended no more than 500 rows be in one import per spreadsheet. If there are more than 500 records, break up the records into several imports.
2. First Name – or Given or Christian name.
3. Last Name or Surname.
4. MRN, local primary key identifier of the Patient in the Hospital PAS.
5. Date of Birth: patient’s date of birth.
6. Date of Admission: date that the patient was actually admitted to acute care or inpatient unit of the hospital. This is not the date of arrival to ED.
7. The First Name, Last Name, Date of Birth, Medicare number, Hospital Identifier and Admission date will create a new instance for the patient. If a duplicate is detected during import processing the data will be updated to the database for that patient instance.
8. Refer to the Data Dictionary for specific definitions of data values.
9. Refer to the ImportSpecification.xls for data specifications.

Data Mapping

Refer to the spreadsheet ImportSpecification.xls for specific instructions for each coloumn attribute. This document specifies the meta-data characteristics for each of the imported data values. The following specifications are covered:

1. Optionality & Notes – whether the attribute is mandatory or optional and any clarification notes.
2. Representation Class – broad information category (text, identifier, code etc.)
3. Data Type – is always String
4. Format – where applicable a representation of how the data is formatted.
5. Max character length – the maximum length of the valid string.
6. Scope of Values & Notes – where applicable lists the scope of all possible values and notes on usage for correct data mapping.

Uploading/Committing Data

It is possible for users to upload data directly to AuSCR through the web interface. The AuSCR system will return a message if successful, if there is a problem with the data the AuSCR system will return a row number and error message to identify the problem. The system will not allow data to commit until all errors have been resolved.

Initially users will send their data as an encrypted attachment to the AuSCR office where the data is analysed and uploaded to the AuSCR system. Feedback will be provided to the hospital user and or local IT support to improve the quality of the imported data and facilitate data entry.

Attachment 1 – Example of Patient Information Sheet

AuSCR
Australian Stroke Clinical Registry

Information for patients and relatives

What is the Australian Stroke Clinical Registry (AuSCR)?

The Australian Stroke Clinical Registry is an electronic data management system that collects information about what happens to people who have had a stroke or a 'mini-stroke', called a transient ischaemic attack (TIA).

The Stroke Registry collects information from hospital information systems to tell us how well you have recovered after your stroke. In order for the Stroke Registry to be successful we hope as many people as possible participate.

Why do we collect information for the Australian Stroke Clinical Registry?

Stroke affects more than 50,000 people in Australia every year and by collecting information about your hospital stay, the Stroke Registry aims to:

- ensure that patients and their families affected by stroke receive the best possible care
- improve stroke care and rehabilitation across Australia
- improve stroke treatment in hospitals
- prevent stroke from occurring, and
- improve chances of recovery after stroke.

Who manages the Stroke Registry?

The Stroke Registry is co-coordinated by The George Institute for International Health affiliated with the University of Sydney.

In your area, the Stroke Registry is managed at _____ _____

[name of hospital] *[name of local investigator]*

What information is collected, when and by whom?

In hospital

After you have agreed to participate, your treating specialist and/or nursing staff will complete the form that contains your details during your time in hospital. This form includes the following information;

- your name
- date of birth
- your country of birth
- your preferred language
- your address
- your telephone and/ or mobile number
- contact details of your next of kin or health contact person
- Medicare number
- hospital identification number
- name of the hospital
- type of stroke
- medical treatment and care, in hospital
- complications, if any
- living arrangements after discharge from hospital

This information is necessary to accurately link a person's hospital stay with any subsequent rehabilitation. This information allows us to collect further information regarding your health care needs from other linked hospital information systems so we know how well you have recovered.

After discharge

As a participant of the stroke registry, you will be contacted either by telephone or mail at approximately 3-6 months after your discharge from hospital, unless a request has been made not to be contacted. At this time the following information will be collected:

- your name
- date of birth
- address
- current health condition
- living arrangements
- support that you have received since leaving hospital.
- If after discharge you need more care, rehabilitation or are admitted back to hospital, information about your ongoing care will also be collected.

How will we keep your information confidential?

All personal information is kept strictly confidential and cannot be used outside the Registry. Information is stored in a specially designed password protected database which can only be accessed by a small number of approved Stroke Registry staff who have a security password to open the database.

Once your information is entered into the registry, it will be given a unique identification number for analysis.

This means that your name will not be identified in any reports that are produced, and your privacy and confidentiality will be maintained.

AuSCR Information Sheet for Patient and Relatives and Consent _Finalv7_31052010

How will your information be used and reported?

Your information is protected and we are not allowed to identify you by law. The Stroke Registry will produce reports on factors that influence the success of stroke care and rehabilitation; aspects of such reports may be presented at conferences or submitted for publication in medical journals. It will not be possible to identify any individuals in any reports.

To maintain absolute security and confidentiality, anyone wanting to use any of the data from the Registry will be required to obtain ethics approval from an Ethics Committee.

What are the risks and benefits to you?

There are no risks to your health by having your details stored in the Stroke Registry. It is anticipated that information in the Stroke Registry will be used to further medical knowledge and improve stroke patient care. After discharge, all participants will have the opportunity to ask to speak with a representative of the National Stroke Foundation about available services at the end of their 3-6 month follow-up. However no direct benefit to you as an individual may be forthcoming from your participation in the Registry.

Will this affect your care?

No, being involved in the Stroke Registry will not affect the way your treating doctors and stroke team approach your treatment or long-term care.

Participation is Voluntary

Participation is voluntary. To remove all or some of your details from the Australian Stroke Clinical Registry, please use the form at the bottom of this page or contact the Stroke Registry on 1800 673 053 (freecall). The signed slip can be given to the nursing staff while you are in hospital, or mailed at anytime to **AuSCR, c/- TGI PO Box M201, Missenden Road, Sydney NSW 2050**.

If you choose to remove Medical information and/or Personal information on the form below, you will be contacted to confirm the specific information you wish to have removed. Please provide your contact details for AuSCR office staff to contact you.

An invitation from the Stroke Registry to participate in future research projects

During your follow-up, you will be asked if you would like to be contacted in the future to receive more information about stroke or participate in future research studies that might be appropriate for you

A decision on whether or not you wish to be contacted about future research projects does not affect your registration in the Registry. If you agree, the Registry staff will be responsible for contacting you. You are under no obligation to participate and can change your mind at any time.

If you have any questions about the Stroke Registry, would like further information, or have any other Registry-related issues please contact **AuSCR Project Coordinator on telephone 1800 673 053 or email admin@auscr.com.au.**

Any person with concerns or complaints about the Stroke Registry can contact the Executive Officer of the (insert name of Research Ethics Committee) on (Insert phone number) or email: (insert email)

The Stroke Registry project has been approved by the .....

[name of relevant research ethics committee].

OPT-OUT FORM *Please tick the box next to the information you do not want recorded in the Registry Database*

I do not wish to have the following information included in the Australian Stroke Clinical Registry (AuSCR):

☐ Medical information *(information about your stroke)*

☐ Personal information *(information such as your date of birth, address, and GP contact details)*

I do not wish to be ☐ contacted after discharge and asked about how I am managing *(known as follow-up)*

Patient Name:..... Date of Birth .....

Phone/ Mobile contact: .....

Signature: ..... Date: .....

AuSCR Information Sheet for Patient and Relatives and Consent _Finalv7_31052010

Attachment 2 – Example of Opt out Form

Opt Off Request

Removing information from the Australian Stroke Clinical Registry database

AuSCR Australian Stroke Clinical Registry

Please send this form to the AuSCR office. Hospitals should also retain a copy of this form in the hospital medical record to document the patient's decision **NOT** to join the Stroke Registry.

I have read the Stroke Registry patient information sheet. I understand the purpose and the benefits of my details and medical records entered into the Stroke Registry.

I also know that I have a choice to request exclusion from any section of the Stroke Registry and at anytime.

Please ☑ tick the information that you would like removed from the Stroke Registry:

Personal information about me

- ☐ Name
- ☐ Medicare Number
- ☐ Date of Birth
- ☐ Country of Birth
- ☐ My address
- ☐ My mobile number
- ☐ Telephone numbers/s of my Next of Kin and/or Alternate Contacts
- ☐ Name of my GP
- ☐ GP Telephone number
- ☐ Title (Mr, Mrs, etc)
- ☐ Gender
- ☐ Aboriginal/Torres Strait Islander status
- ☐ Language spoken
- ☐ My telephone number
- ☐ Name/s of my Next of Kin and/or Alternate Contacts
- ☐ Address/s of my Next of Kin and/or Alternate Contacts
- ☐ GP address
- ☐ All of my personal information

Information about my stroke and care I received in hospital

- ☐ Date of the onset of the stroke
- ☐ Date of arrival to Emergency Department
- ☐ Date of admission to hospital
- ☐ Whether or not this was your first stroke
- ☐ Whether you were able to walk when you were admitted to hospital
- ☐ If you were treated in a Stroke Unit
- ☐ Date of discharge from hospital
- ☐ If you were given a careplan at discharge
- ☐ Date of death if applicable
- ☐ Time of the onset of the stroke
- ☐ Time of arrival to Emergency Department
- ☐ Whether you were transferred from another hospital
- ☐ Whether the stroke occurred while you were in hospital
- ☐ Hospital codes that define your diagnosis, medical condition, and any complications or procedures
- ☐ Type of stroke
- ☐ Discharge destination
- ☐ If you received an Antihypertensive agent at discharge
- ☐ All of my stroke and hospital care information

☐ Being contacted and having follow–up details recorded in the Stroke Registry (eg. support services, who I live with, and my quality of life)

☐ All of the above information

---------- ----------

Patient's Name *Name of Hospital*

---------- ----------

Signature of Patient/Authorised proxy *Date*

For more information about the Australian Stroke Clinical Registry please call the *AuSCR Project Coordinator* on telephone 1800 673 053 or visit our website at www.auscr.com.au

Postal: PO Box M201, Missenden Road, Sydney NSW 2050 Australia
Fax: Attention AuSCR: (02) 9993 4502

Opt off_FormV4_250609

Attachment 3 – Example of Acute Data Collection Form

DATA COLLECTION FORM

AuSCR
Australian Stroke Clinical Registry

Please complete the form:
- Neatly and legibly
- Write in **black ink** and press firmly
- Each question must be completed;
- Place ☑ in appropriate boxes.
- Required fields marked with * must be completed

Return form to AuSCR Office via
- Fax: (02) 8507 2531

Or
- Post: AuSCR Office, c/o TGI PO Box M201,
- Missenden Road, Camperdown, NSW 2050.

Hospital Name:

AFFIX PATIENT STICKER HERE

Patient Information

Title

First Name*

Last Name*

Address type ☐ Home ☐ Business ☐ Other

Street Address

Suburb

Post Code State

Country

Phone Number Mobile Number

Medicare No Hospital MRN*

Date of Birth * (dd/mm/yyyy) Gender ☐ Male ☐ Female

Country of birth

Language spoken

Interpreter needed ☐ Yes ☐ No

Is the patient of Aboriginal and/or Torres Strait Islander origin?*
- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☐ Neither Aboriginal nor Torres Strait Islander origin

Acute Data Collection Form v3.1 17082010

Patient Name: _____ DOB: ___/___/_____ Hospital: _____

Emergency Contact

First Name
Last Name
Address type ☐ Home ☐ Business ☐ Other
Street Address
Suburb
Post Code State
Country
Phone Number Mobile Number
Relationship to participant

Alternate Contact

First Name
Last Name
Address type ☐ Home ☐ Business ☐ Other
Street Address
Suburb
Post Code State
Country
Phone Number Mobile Number
Relationship to participant

General Practitioner

GP First Name
GP Last Name
Street Address
Suburb
Post Code State
Country
GP Telephone Number
GP Fax Number

Patient Name: _____ DOB: ___/___/_____ Hospital: _____

Admission Information

Date of arrival at Emergency Department* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Time of arrival at Emergency Department* ☐☐:☐☐ (24-hour clock) ☐ Accurate ☐ Estimate

Date of stroke onset* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Time of stroke onset* ☐☐:☐☐ (24-hour clock) ☐ Accurate ☐ Estimate

Date of admission* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Was the patient transferred from another hospital?*	☐ Yes	☐ No	☐ Unknown
Did this stroke occur while the patient was in hospital?*	☐ Yes	☐ No	☐ Unknown
Able to walk independently on admission?* (i.e. may include walking aid, but without assistance from another person)	☐ Yes	☐ No	☐ Unknown
Is there documented evidence of a previous stroke?* (i.e. focal neurological signs persisting for more than 24 hours)	☐ Yes	☐ No	☐ Unknown

Clinical Information

Was the patient treated in a Stroke Unit at any time during their stay?* ☐ Yes ☐ No ☐ Unknown

Type of stroke* ☐ TIA ☐ Ischaemic ☐ Haemorrhagic ☐ Undetermined

If an ischaemic stroke,did the patient receive intravenous thrombolysis (tPA)?* ☐ Yes ☐ No ☐ Unknown

Cause of stroke * ☐ Known ☐ Unknown

ICD10 code – Diagnosis ☐☐☐☐☐

Separation (Discharge) Information

Patient Deceased ☐ No ☐ Yes, date of death: ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Discharged Alive

a) Date of discharge* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

b) Discharge destination/mode*

☐ Hospital
☐ Rehabilitation (Inpatient)
☐ Low level Residential Care
☐ High level Residential Care
☐ Home with support
☐ Home without support
☐ Transitional care services
☐ Died in hospital
☐ Other: _____

c) Discharged with antihypertensive agents* ☐ Yes ☐ No ☐ Unknown

d) Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)?* ☐ Yes ☐ No ☐ Not applicable ☐ Unknown

Opt-Out Request

Place ☑ in appropriate boxes

☐ Medical information ☐ Personal information ☐ Do not wish to be contacted for *follow-up*

Form completed by: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Date: ☐☐/☐☐/☐☐☐☐ Contact Number ☐☐☐☐☐☐☐☐☐☐

Attachment 3a – Example of Correctly completed Acute Data Collection Form

Correctly completed Data Collection Form

DATA COLLECTION FORM

AUSCR Australian Stroke Clinical Registry

Please complete the form:

- Neatly and legibly
- Write in **black ink** and press firmly
- Each question must be completed;
- Place ☑ in appropriate boxes.
- Required fields marked with * must to filled

Return form to AuSCR Office via

- Fax: (02) 8507 2531

Or

- Post: AuSCR Office, c/o TGI PO Box M201, Missenden Road, Camperdown, NSW 2050.

Hospital Name: ROYAL JOHNS HOSPITAL: HEAVENSVILLE (RJHH)

B009085
BLOGGS, OSCAR M
12 Registry Street
Heavensville
2150
M-
DOB 12/12/1921

Patient Information

Title: MR

First Name*: OSCAR BLOGGS

JMP 9/8/09

Last Name*: BLOGGS

Address type: ☑ Home ☐ Business ☐ Other SEE PATIENT STICKER

Street Address:

Suburb:

Post Code: State* NSW

Phone Number* 0291811234 Mobile Number 0765865 11

Medicare No. 1234567891 Hospital MRN B009085

Date of Birth: (dd/mm/yyyy) Gender ☐ Male ☐ Female

Country of birth: AUSTRALIA

Language spoken: ENGLISH

Interpreter needed ☐ Yes ☑ No

Is the patient of Aboriginal and/or Torres Strait Islander origin?*

- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☑ Neither Aboriginal nor Torres Strait Islander origin

created 19 June 2009

1

OSCAR BLOGGS DOB 12/12/21 RJHH

Emergency Contact

First Name: MARY

Last Name: CREAM

Address type: ☑ Home ☐ Business ☐ Other SEE PATIENT STICKER

Street Address:

Suburb:

Post Code: State: NSW

Phone Number: Mobile Number:

Relationship to participant: SPOUSE

Alternate Contact

First Name: JOSEPH

Last Name: BLOGGS

Address type: ☑ Home ☐ Business ☐ Other

Street Address: 20 FREDDIE STREET

Suburb: HEAVENSVILLE

Post Code: 2150 State: NSW

Phone Number: 0291815678 Mobile Number: 0766666

Relationship to participant: SON

General Practitioner

First Name: JOHN

Last Name: SMITH

Street Address: 50 RED STREET

Suburb: COLOURSVILLE

Post Code: 2151 State: NSW

created 19 June 2009

2

GP Telephone Number

Mobile Number

Admission Information

Date of arrival at Emergency Department* 09/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of arrival at Emergency Department* 09:45 (24-hour clock) Estimated time: ☐

Date of stroke onset* 09 08/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of stroke onset* 02:00 (24-hour clock) Estimated time: ☑

Date of admission* 09/08/2009 (dd/mm/yyyy)

Was the patient transferred from another hospital?*	☐ Yes	☑ No	☐ Unknown
Did this stroke occur while the patient was in hospital?*	☐ Yes	☑ No	☐ Unknown
Able to walk independently on admission?* (i.e. may include walking aid, but without assistance from another person)	☐ Yes	☑ No	☐ Unknown
Is there documented evidence of a previous stroke? (i.e. focal neurological signs persisting for more than 24 hours)	☐ Yes	☑ No	☐ Unknown

Clinical Information

Was the patient treated in a Stroke Unit at any time during their stay?* ☐ Yes ☐ No ☐ Unknown

Type of stroke* ☐ TIA ☑ Ischaemic ☐ Haemorrhagic ☐ Undetermined

If an ischaemic stroke, did the patient receive intravenous thrombolysis (tPA) ☐ Yes ☐ No ☐ Unknown

Cause of stroke * ☐ Known ☐ Unknown

ICD10 code – Diagnosis

Separation (Discharge) Information

Patient Deceased ☐ No ☐ Yes, date of death: (dd/mm/yyyy) Estimated date: ☐

Discharged Alive

a) Date of discharge* (dd/mm/yyyy) Estimated date: ☐

b) Discharge destination/mode*

- ☐ Hospital
- ☐ ~~Rehabilitation (Inpatient)~~
- ☐ Low level Residential Care
- ☐ High level Residential Care
- ☐ Other:
- ☐ Home with support
- ☐ Home without support
- ☐ Transitional care services
- ☐ Died in hospital

c) Discharged with antihypertensive agents* ☐ Yes ☐ No ☐ Unknown

d) Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)?* ☐ Yes ☐ No ☐ Not applicable ☐ Unknown

Form completed by:

Date: Contact Number

created 19 June 2009

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Attachment 3b – Example of Poorly completed Acute Data Collection Form

Incorrectly completed Data Collection Form

DATA COLLECTION FORM

AuSCR Australian Stroke Clinical Registry

Please complete the form:

- Neatly and legibly
- Write in **black ink** and press firmly
- Each question must be completed;
- Place ☑ in appropriate boxes.
- Required fields marked with * must to filled

Return form to AuSCR Office via

- Fax: (02) 8507 2531

Or

- Post: AuSCR Office, c/o TGI PO Box M201, Missenden Road, Camperdown, NSW 2050.

Hospital Name:

B009085
BLOGGS, OSCAR M
12 Registry Street
Heavensville
2150
M-
DOB 12/12/1921

Patient Information

Title: MR

First Name*: OSCAR BLOGGS

Last Name*: BLOGGS

Address type: ☐ Home ☐ Business ☐ Other

Street Address:

Suburb:

Post Code: State*:

Phone Number*: Mobile Number:

Medicare No.: Hospital MRN:

Date of Birth: (dd/mm/yyyy) Gender: ☐ Male ☐ Female

Country of birth: AUSTRALIA

Language spoken: ENGLISH

Interpreter needed: ☐ Yes ☑ No

Is the patient of Aboriginal and/or Torres Strait Islander origin?*

- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☑ Neither Aboriginal nor Torres Strait Islander origin

Emergency Contact

First Name: MARY

Last Name: CREAM

Address type: ☐ Home ☐ Business ☐ Other

Street Address:

Suburb:

Post Code: State:

Phone Number: Mobile Number:

Relationship to participant: SPOUSE

Alternate Contact

First Name:

Last Name:

Address type: ☐ Home ☐ Business ☐ Other

Street Address:

Suburb:

Post Code: State:

Phone Number: Mobile Number:

Relationship to participant:

General Practitioner

First Name: NIL

Last Name:

Street Address:

Suburb:

Post Code: State:

GP Telephone Number

Mobile Number

Admission Information

Date of arrival at Emergency Department* 09/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of arrival at Emergency Department* 09:45 (24-hour clock) Estimated time: ☐

Date of stroke onset* 09 08/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of stroke onset* 02:00 (24-hour clock) Estimated time: ☑

Date of admission* 09/08/2009 (dd/mm/yyyy)

Was the patient transferred from another hospital?*	☐ Yes	☑ No	☐ Unknown
Did this stroke occur while the patient was in hospital?*	☐ Yes	☑ No	☐ Unknown
Able to walk independently on admission?* (i.e. may include walking aid, but without assistance from another person)	☐ Yes	☑ No	☐ Unknown
Is there documented evidence of a previous stroke? (i.e. focal neurological signs persisting for more than 24 hours)	☐ Yes	☑ No	☐ Unknown

Clinical Information

Was the patient treated in a Stroke Unit at any time during their stay?* ☐ Yes ☐ No ☐ Unknown

Type of stroke* ☐ TIA ☑ Ischaemic ☐ Haemorrhagic ☐ Undetermined

If an ischaemic stroke, did the patient receive intravenous thrombolysis (tPA) ☐ Yes ☐ No ☐ Unknown

Cause of stroke * ☐ Known ☐ Unknown

ICD10 code – Diagnosis

Separation (Discharge) Information

Patient Deceased ☐ No ☐ Yes, date of death: (dd/mm/yyyy) Estimated date: ☐

Discharged Alive

a) Date of discharge* (dd/mm/yyyy) Estimated date: ☐

b) Discharge destination/mode*

- ☐ Hospital
- ☐ ~~Rehabilitation (Inpatient)~~
- ☐ Low level Residential Care
- ☐ High level Residential Care
- ☐ Other:
- ☐ Home with support
- ☐ Home without support
- ☐ Transitional care services
- ☐ Died in hospital

c) Discharged with antihypertensive agents* ☐ Yes ☐ No ☐ Unknown

d) Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)?* ☐ Yes ☐ No ☐ Not applicable ☐ Unknown

Form completed by:

Date: Contact Number

created 19 June 2009

3

Attachment 4 – Data Dictionary provided to your Hospital

The data dictionary is also available on the AuSCR website at:
http://www.auscr.com.au/health-professionals/forms-manuals/hospital-user-manual/

Attachment 5 – Example of User Request Form

Australian Stroke Clinical Registry

AuSCR Online Tool
User Request Form

Please complete this form to obtain a user ID and password to be able to log in to the AuSCR Online Tool.

* required field

Title _____ **Name*** _____

Position _____

Hospital* _____

Email* _____ **Phone*** _____

Signature _____

Access Request for *
(Tick appropriate box)

☐ Hospital Administrator ☐ Hospital User ☐ Follow- up User

Please note that this request must be authorised by the AuSCR:

- Project Coordinator for Hospital Administrator and Follow- up User Request
- Hospital Administrator for Hospital User Request

Authorised by* _____ Title _____

Email* _____ Phone _____

Please return this form by fax or email. If you have any questions, please do not hesitate to contact us.

Project Coordinator
Australian Clinical Stroke Register
(AuSCR)
C/- The George Institute
PO Box M201 Missenden Rd
SYDNEY NSW2050

Email: admin@auscr.com.au
Telephone: (02) 9993 4592
Fax: (02) 9993 4502

Office Use Only

_____ _____ _____ _____ _____
Date received *Date created* *User name* *Password assigned*

User Request Form (28 july) v4

Attachment 6 - Example of Patient Contact Letter Post Discharge

[HOSPITAL LETTERHEAD]

[Date]

Dear [NAME]

We wish to inform you that your hospital [*hospital name*] is participating in the Australian Stroke Clinical Registry (AuSCR), which is a national stroke register to collect important information about what happens to people who have had a stroke or a 'mini-stroke', called a transient ischaemic attack (TIA). Because you (or your family member), were recently in hospital with a stroke, the details have automatically been given to us. We wish to contact you to clarify some details about the illness. The information we collect about the treatment given in hospital will enable us to make contact with you at three to six months after the stroke so that we can assess the degree of recovery and any ongoing health problems. This information is important to use as it will allow health care planners and doctors to improve the care that patients with stroke receive in hospital.

We have enclosed a copy of the **AuSCR Patient Information Sheet**, which we hope you will take the time to read, as it provides more details about AuSCR. In brief, it is a national initiative that is supported by The Australian Commission on Safety and Quality in Health Care, the National Stroke Foundation, and the Stroke Society of Australasia. It has been approved by the Human Research Ethics Committee at [*local hospital*]. Participation is entirely voluntary and any information you provide will be treated as strictly confidential. The AuSCR database has been specially designed to ensure that your name never be used to identify you to ensure that your privacy is maintained. Neither your identity or personal details will be revealed in any publications or made available to outside organisations.

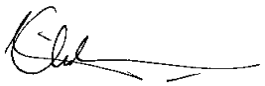
If you do not wish to participate, please indicate this on the opt-off form at the bottom of the Information Sheet and return it to us at:

AuSCR Project Office
The George Institute
PO Box M201
Missenden Road NSW 2050

If we have not heard from you within two (2) weeks, we will assume that you are willing to have your details recorded. If you have any questions, concerns or complaints about AuSCR, please contact the Project Coordinator on telephone 1800 673 053 or email admin@auscr.com.au.

Any person with concerns or complaints about the Stroke Registry may also contact the Executive Officer of the relevant Ethics Committee on telephone [ ] or email [email@email.com.au].

Yours faithfully,



SIGNATURE
[Name of Patient's Primary/Treating Physician]
[*Title*]
[*Name of Hospital*]
Enc. Patient Information sheet

SIGNATURE
Professor Craig Anderson
AuSCR Chief Investigator